

# End-of-life care and physician-assisted dying

1 Setting the scene 2 Public dialogue research 3 Reflections and recommendations





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- 1. Setting the scene**
- 2. Public dialogue research**
- 3. Reflections and recommendations**

**This volume is the first of a three part report on a BMA project on end-of-life care and physician-assisted dying. The project was overseen by a steering group appointed by BMA council, working with a staff project team from across the BMA.**

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## Foreword from the project and steering group chair

All lives end.

Whilst cultural norms vary, in the UK discussions about death and dying tend to be thought uncomfortable – perhaps leaving fears and uncertainties unaddressed, and knowledge lacking.

The UK has led the world in developing pathways and strategies for comprehensive and holistic care for those whose lives are coming to an end and the standards and quality of what *can* be provided. Yet the provision of and access to such care remains variable, dependent on a patient's geographical location; their condition; and their knowledge of local systems. Options and choices at the end of life have recently received unparalleled scrutiny in the media, popular culture, the academic community, and in legislatures – from care pathways and care bundles through to assisted dying. Most recently, and at the time of writing, a private member's bill seeks to widen access to and improve provision of palliative care.

These issues elicit a range of responses and often impassioned, polarised opinion, making it hard to consider qualitative, nuanced factors. It is against this backdrop that the BMA launched a project examining public and professional attitudes and understanding around end-of-life care issues and options. The approach has been designed to allow consultation and discussion with both doctors and the public in a structured qualitative dialogue, designed to obtain a richness of information, opinion and understanding. The aim is to increase our understanding and support discussions around these difficult areas – advising our decisions and deliberations, both within the BMA and in public debate.

This project report contains three parts:

- Part 1 (this volume) seeks to set the scene against which the qualitative research commissioned by the BMA has been conducted, outlining the context in which public, parliamentary, and professional debate has been conducted, and bringing together both peer-reviewed research and surveys of opinion. It is a literature review, not a systematic review; it does not seek to state the BMA's views or make value-judgements on the included materials. While the breadth of this review is extensive, the project team is aware of the gaps in what could be achieved in this volume – particularly in the field of managing pain, although noting that the BMA Board of Science is planning a major new report which will explore pain relief in palliative care as well as in other conditions. There is also only limited focus on children although there are profound implications both for children who are themselves dying and for children who have been bereaved.
- Part 2 will be published alongside this volume, and constitutes unique, independently commissioned qualitative research into patients' and doctors' fears and concerns; their perceptions and attitudes about the end of life and dying; perceptions and experiences of the availability, accessibility, and quality of end-of-life care in the UK; and the potential impact any legislative change around assisted dying might have on doctor-patient relationships.
- Part 3 will bring together responses to the research and subsequent discussions with groups of members and experts in the fields. It will propose recommendations on areas where there is room to improve or potential to expand our knowledge, and will address both practical and ethical issues. This volume will be published in the run-up to the BMA's Annual Representative Meeting, which is taking place in June 2016.

It is my hope that this report will make a significant contribution to the Association's own debates and discussions and inform future BMA work in this area. These issues have much broader interest and relevance, extending far beyond the medical profession, and so I hope that this report will also play a role in the continuing public dialogue, and most importantly, make a contribution to real, sustained, change.

**Dr Ian Wilson**  
**Project and steering group chair**  
**BMA Representative Body Chair**

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## Introduction

The medical profession plays a key role in treating, supporting and caring for patients and their families at the end of life. The level, type and standard of care provided to those facing death, both within the NHS and beyond, and the options available to patients, are therefore issues of crucial importance to doctors and, in our role of providing support to our members, to the BMA. It is not only doctors who are interested in these issues and it needs to be acknowledged that a huge amount of work has gone into trying to improve the accessibility and quality of end-of-life care, by governments, charities and other organisations. Numerous reports have been written about the care that should be available, care strategies have been put in place and good practice standards discussed; but how far are these standards being met around the UK? It is clear from reports, such as that from the Health Service Ombudsman,<sup>1</sup> and the review of the Liverpool Care Pathway,<sup>2</sup> that care does not always work well. But focussing solely on these extreme and often tragic cases, can disguise the overall picture of what is happening well every day of the week in hospitals, hospices, care homes and GP practices across the UK.

We are interested in understanding how the 'lived experiences' and perceptions of our members and the public meet the paper vision. We are interested in what works well, and what works less well, what the challenges are and how they might be overcome. We want to know whether some groups fare better than others within the system and whether there are steps that can be taken to help our members to provide the best possible quality of care to all of their patients who are approaching the end of their lives. This is about hearing from those with direct experience of end-of-life care and those without because people's perceptions of the quality and accessibility of care, whether accurate or not, can be very powerful in influencing their views, hopes and fears about developing a serious illness and approaching death.

For some patients, the choice they want is not available to them: to choose the time and method of their death with medical assistance through physician-assisted dying. If opinion polls are to be believed a large proportion of the public supports the legalisation of assisted dying but the BMA has concerns and opposes any change in the law. Our policy is made through a long-established, democratic process at our annual representative meeting (ARM) where motions are submitted, debated and voted upon. Part of the 'transformation' that the BMA has been undergoing over the last few years, however, is a desire to broaden our evidence base and to capitalise on the wealth of knowledge and experience we have within our wider membership. Whilst inevitably not every BMA member will support every one of our policies, on significant topics such as this we are keen to engage beyond those who are politically active within the BMA and also hear from some of our members who are far removed from the world of medical politics. Through projects such as this we are seeking to hear from a broader range of our members and to feed those views into our decision-making process.

Assisted dying will undoubtedly continue to be debated in the coming years, both within our membership and within society more generally. We want to ensure that our debates are informed and thoughtful. This is not a binary issue – it is a complex and emotive topic which does not lend itself easily to simple yes or no survey-type questions and so we are keen to explore some of the ethical and practical issues in more detail than is possible through that format. This is about people's perceptions – about the public's and doctors' perceptions of the impact of introducing assisted dying legislation on the doctor-patient relationship, for example, which has always been a key concern raised in our debates on the topic. In discussing these wider issues it is important to try to include those who have less firmly established views as well as those who campaign regularly on the issue. Surveys have their place, but we are keen to have some more in-depth consideration, reflection and debate about this issue. What is lost in terms of hard data and easily quotable statistics is, in our view, more than made up for by the richness of the information and the deeper understanding of the issues that we will be able to call upon in informing our debates.

It was with all of this in mind that in November 2014 BMA Council approved a significant piece of work on end-of-life care and physician-assisted dying of which this volume is one part. We engaged social research specialists TNS BMRB to develop and conduct, on our behalf, a series of events around the UK with the public and with our members, to explore views and perceptions about these issues. We held 10 events with the public and 10 with groups of BMA members in six locations in England, two in Scotland, and one each in Wales and Northern Ireland. In addition, an extra event was held in Liverpool during our annual representative meeting for an invited group of representatives. The project was overseen by a steering group established by BMA Council the membership of which is set out at the beginning of this report. Full details of the events, including recruitment, format and findings are set out in the second volume of this report, prepared by TNS BMRB.

### Terminology

At the beginning of this project, in order to clarify its scope and to ensure a common understanding amongst participants and readers, we set out to define our terms, including what we meant by 'end-of-life care' and 'physician-assisted dying'. Neither concept is straightforward, and different people have preferences for different terminology. We have therefore set out clearly below the definitions we have used for the purposes of this project. It is important to be clear, however, that these terms are used as descriptors only, to describe the broad parameters of our work; we ascribe no value or moral judgement to the activities they describe by the choice of these terms, rather than any others we could have chosen.

We chose a broad definition of end-of-life care but nonetheless, we are aware that this may not fully encapsulate all of the cases we wanted to include. We were keen, for example, to encompass both those diagnosed with a 'terminal' illness (however that is defined) and the large and increasing group of frail elderly patients with multiple co-morbidities who are also approaching the end of their lives. The definition used to inform the discussion at the public events is in the box below but very broadly, we were referring to the stage from which it is decided that curative treatment is no longer able to provide a benefit to the patient and that the focus should shift to managing symptoms and distress to maximise quality of life, and ensuring the patient receives good quality care. We recognise, of course, that many patients will continue curative treatment until very close to death whereas others will receive curative treatment for some conditions and not others. 'Palliative care' is often used interchangeably with end-of-life care.

**End-of-life care:** refers to the total care of a person with an advanced incurable illness and does not just equate with dying. The end-of-life care phase may last for days, weeks, months or even longer. It is defined as care that helps those with advanced progressive, incurable illness to live as well as possible until they die. It includes the prevention and relief of suffering through the assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

The definition of physician-assisted dying used for this project (see box below) was intended to capture all *active* steps by doctors to assist an individual to end their life but not decisions by, or on behalf of, the patient to stop treatment, or the use of opioids or sedatives where the intention is to ease the patient's pain and suffering and the dosage is proportionate to that intention. Physician-assisted dying is used as an overarching term to include both cases where the final action is taken by the patient (assisted suicide) and where the doctor administers the lethal dose (euthanasia). We recognise that some people dislike the term 'assisted dying', believing it to be a euphemism for euthanasia or assisted suicide and an attempt to 'sanitise' the discussion. Some argue that this term is misleading and that it is the patient's 'death' that is assisted not 'dying', since doctors have a clear and important role in assisting patients through the dying process by the provision of palliative care, pain relief and practical and emotional support. In order to avoid this confusion the term 'physician-assisted death' is preferred by some. Other terms are equally controversial. Some, for example, believe that where individuals are dying and have no hope of recovery their request for assistance to die should not be classed as suicide and so reject the term physician-assisted suicide. Given the very strong, and opposing, views held on this topic, it is difficult

to find any term that is viewed by those on all sides of the debate as neutral and purely descriptive. We have therefore opted for the definition below but with the caveat stated above – that it is used in purely descriptive terms and must not be interpreted as making any value judgements whatsoever.

**Physician-assisted dying:** an overarching term to describe physician involvement in measures intentionally designed to terminate a patient's life. This may include knowingly and intentionally providing a person with the knowledge and/or means required to end his or her life, including counselling about lethal doses of drugs and prescribing such lethal doses or supplying the drugs. Administration of the drug may be by the individual him or herself (physician-assisted suicide) or by the physician or another person (euthanasia).

### This volume

During the preparation for the events with the public and doctors, a lot of information was gathered together about the subjects to be covered, both to clarify the topics for discussion but also to provide the backdrop against which the events took place. It is important to know what care is theoretically available for patients at the end of life, in order to assess the public and doctor's experiences and perceptions of how well this is being achieved. Also, if our aim is to have an informed discussion within our membership, it is reasonable for our members to expect us to provide that information in an easily accessible form. This volume is not a systematic, scientific review of the evidence; but rather, brings together relevant information in a single report in order to facilitate informed debate both within our membership and beyond.

The main focus of this report is on adults, although some aspects of the report are also applicable to the care of children and young people. Similarly, we recognise that there are specific considerations that need to be taken into account when caring for particular groups of patients, such as those with learning disabilities or dementia, and that there are particular difficulties they face in relation to end-of-life care, but these are not explored in detail in this report. Even with these limitations, the information provided is, by no means, exhaustive; given the vast literature on these wide-ranging topics, such a task would be unachievable. We have also avoided offering comment or conjecture in this volume, focussing instead on providing factual information in a balanced way. Clearly, however, there is little benefit in conducting such a significant piece of work without giving careful thought to the findings and seeking to learn from them. The third element of this project is therefore a more thoughtful reflection on both the factual information contained in this volume and the findings of the events; this will be published in the third volume of this report which will follow once we have had time to properly consider the findings.

## Chapter 1

# End-of-life care in the UK



# Chapter 1

## End-of-life care in the UK

The provision of end-of-life care in the UK has received a lot of attention in the last few years, underpinned by a desire to improve care for patients. In recent years, all four constituent nations of the UK have published national end-of-life care strategies and supporting policies, outlining what should be available to all those in need of end-of-life and palliative care. One aim of the events for this project was to understand whether these national strategies aligned with the public and doctors' perceptions of what was actually available in their local areas.

This chapter analyses the available statistical and academic evidence on the provision, availability and accessibility of end-of-life care in the UK. It also explores some of the perceptions the public and doctors have about end-of-life care and dying, drawing on recent surveys and academic research. There is a vast literature on this topic and this chapter provides a very condensed review of some of the main documents. At the events with doctors and members of the public, views and perceptions were sought on the availability and accessibility of end-of-life care, in order to assess how these compared with the information in this chapter. The findings can be found in the second volume of this report, prepared by TNS BMRB.

### Part One – Background

End-of-life care refers to the total care of a person with an advanced incurable illness and does not just equate with dying. The end-of-life care phase may last for days, week, months or even longer. It is defined as care that helps those with advanced progressive, incurable illnesses to live as well as possible until they die. It includes the prevention and relief of suffering through the assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

In the United Kingdom, this care is provided in a variety of settings and by a variety of professionals. Most palliative care is provided by people for whom care of the dying is not the major focus of their work, including GPs, district nurses, and hospital consultants. Specialist palliative care teams provide in-patient facilities, support generalists providing care in the community and in hospitals, and coordinate services across service providers.

Historically, the UK has been at the forefront of the development of end-of-life and palliative care – in particular, in the birth of the hospice movement, spearheaded by Dame Cicely Saunders. The UK is also one of the few countries worldwide which recognises end-of-life care at a statutory level in healthcare and medical education policies, and which has formal strategies for its provision.<sup>3</sup> These factors were key to the findings of the Economist Intelligence Unit in 2010<sup>4</sup>, when they ranked the UK (jointly with Australia) as number one amongst forty other countries in their “quality of death” index. In October 2015, the Economist Intelligence Unit published its most recent survey in which the UK, once again, was ranked in first place – this time amongst 80 nations – for quality of end-of-life care.<sup>5</sup>

At the same time, however, it is widely acknowledged that the discrepancies in provision between the four home nations (health – including end-of-life care – has been a devolved matter for each of the four constituent nations of the United Kingdom since the late 1990s) and a reliance on the charity sector has led to variation in the nature and quality of end-of-life care service provision.<sup>6,7,8</sup> Examples of poor end-of-life care persist, and given their emotive nature, receive widespread media attention<sup>9</sup> (including, but not limited to the press coverage of the Liverpool Care Pathway, which will be explored in more detail below). Around half of all NHS complaints relate to end-of-life care, indicating that this remains an area for further improvement.<sup>10</sup>

The provision of end-of-life care looks set to become of even more importance in light of the fact that the population of the UK is growing and contains a greater proportion of older people. It is likely that more people will die as the result of cancer and chronic conditions such as dementia, degenerative illnesses, or general frailty. At present, the population of the UK is around 65 million. Of this, 5.2 million are aged 75 or over, and 1.5 million of those are aged 85 or over. By 2039, it is predicted that the total population will increase to 74.3 million, with 9.9 million aged 75 or over, with 3.6 million of those aged 85 or over – double that of the current population aged 85 and over.<sup>11</sup> It has also been predicted that the number of people in England and Wales aged 65 and over with dementia will increase by over 80% to 1.96 million between 2010 and 2030;<sup>12</sup> this will have a significant impact on health professionals and the provision of healthcare services both generally and specifically at the end of life.

## Part Two – Delivery of end-of-life care

As noted above, the United Kingdom is one of the few countries worldwide to have formal frameworks for end-of-life care. The content and format of these frameworks is devolved to the constituent nations, and in recent years, all four have published national end-of-life care strategies and supporting policies.

While the precise content and structure of the frameworks differ across the countries, their core focus is broadly similar. Each of these strategies promote the delivery of high quality palliative care to all individuals who need it (regardless of their medical condition or where they live), by skilled professionals from various relevant teams and services. In all strategies, there is a focus on individual patient need and choice, rather than the adoption of a blanket, one-size-fits-all-approach. In all countries it is perceived as key that those with life limiting conditions whose condition is deteriorating and are thought to be approaching death are identified so that their needs and wishes can be established and communicated to relevant services. This should also include discussion of treatment options in order that patients can make informed decisions about whether to accept or refuse particular interventions.

### The Liverpool Care Pathway

A care pathway is intended as a guide for treatment and aid to recording patient progress. It crosses health and social care and allows practitioners to exercise professional judgement about care provision and treatments within a set framework.

Until July 2014, the main pathway used for the care of dying patients across the UK (excluding Wales) was the Liverpool Care Pathway (LCP). The LCP was developed in the 1990s, in an effort to roll out hospice-type care into other care settings (hospitals, nursing homes, and community care) for the care of patients in the last two to three days of life. The hospice patients mostly had cancer, but the LCP was soon extended to all terminally-ill patients thought to be dying in a matter of days or hours.

The pathway provided:

- alerts, guidance and a structured single record for doctors, nurses, and other members of multidisciplinary teams that are not expert in palliative care;
- a single document for recording initial and ongoing assessments of the patient and a place for messages to be provided between care-givers;
- a flowchart of questions to assess symptoms such as pain, nausea/vomiting, restlessness, and excessive secretions, as well as advice on choice of drugs to control pain; and
- guidance on provision of care and processes to follow after the death of the patient (including who to inform, communication with family/carers etc.).

In 2013, the LCP was heavily criticised in the national media following reports of poor quality care. It was suggested that it was not properly implemented, with some patients living many months after the commencement of the pathway without proper review, and that communication with family and friends was substandard.<sup>13,14</sup> Some media outlets called it “the road to death” and suggested that it was an excuse for doctors to deny elderly patients food and water as well as over-prescribe sedative drugs.<sup>15,16</sup> Others, however, spoke in support of the LCP when implemented properly.<sup>17</sup>

In July 2013 an independent review lead by Baroness Julia Neuberger (“the Neuberger Review”) into the use and effectiveness of the LCP found that, whilst in the right hands it could provide a model of good practice, it had been used improperly in a number of instances. It suggested that a one-size-fits-all approach to end-of-life care was not the right method, and called for the LCP to be removed by July 2014 and replaced by individual plans, backed up by condition-specific good practice guidance.<sup>18</sup>

Following the LCP review, the Leadership Alliance for the Care of Dying People (LACDP), a coalition of national organisations and charities, was established to take forward the recommendations of the Neuberger review. In June 2014, it published *One Chance to Get it Right*, which sets out the approach that health and care organisations and staff caring for dying people in England should adopt in future.<sup>19</sup> As recommended by the Neuberger review, this has not been implemented as a national standard but instead provides guidance to those providing palliative care, requiring them to take into consideration individual circumstances.

The main priorities for care, when it is thought that a person may die within the next few days or hours, are as follows:

1. The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person’s needs and wishes, and these are reviewed and revised regularly.
2. Sensitive communication takes place between staff and the person who is dying and those important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care.
4. The people important to the dying person are listened to and their needs are respected.
5. Care is tailored to the individual and delivered with compassion – with an individual care plan in place.

## 1. England

England has the highest population of all four nations, at nearly 55 million. Around 9.7 million are aged 65 or over and 1.3 million are aged 85 or over.<sup>20</sup> There are around 470,000 deaths each year.<sup>21</sup> In 2013, cancer was the most common cause of death in England and Wales (29% of all deaths registered) followed by circulatory disease, such as heart disease and stroke (28% of all deaths registered).<sup>22</sup>

In July 2008, the Department of Health (DH) published its first end-of-life care strategy for England, which aims to ensure that provision of end-of-life care, with appropriate quality assurance measures and funding, is provided across England.<sup>23</sup>

This strategy incorporates various elements of end-of-life care, including discussion as the end of life approaches; assessment, care planning and review; the coordination of care for individual patients; and the delivery of high quality services in different settings. Alongside patient care, end-of-life care also provides support, information, and spiritual care for the patient’s carers and family, and the strategy explicitly includes care of these individuals *after* the death.

The following diagram shows how these steps fit together:

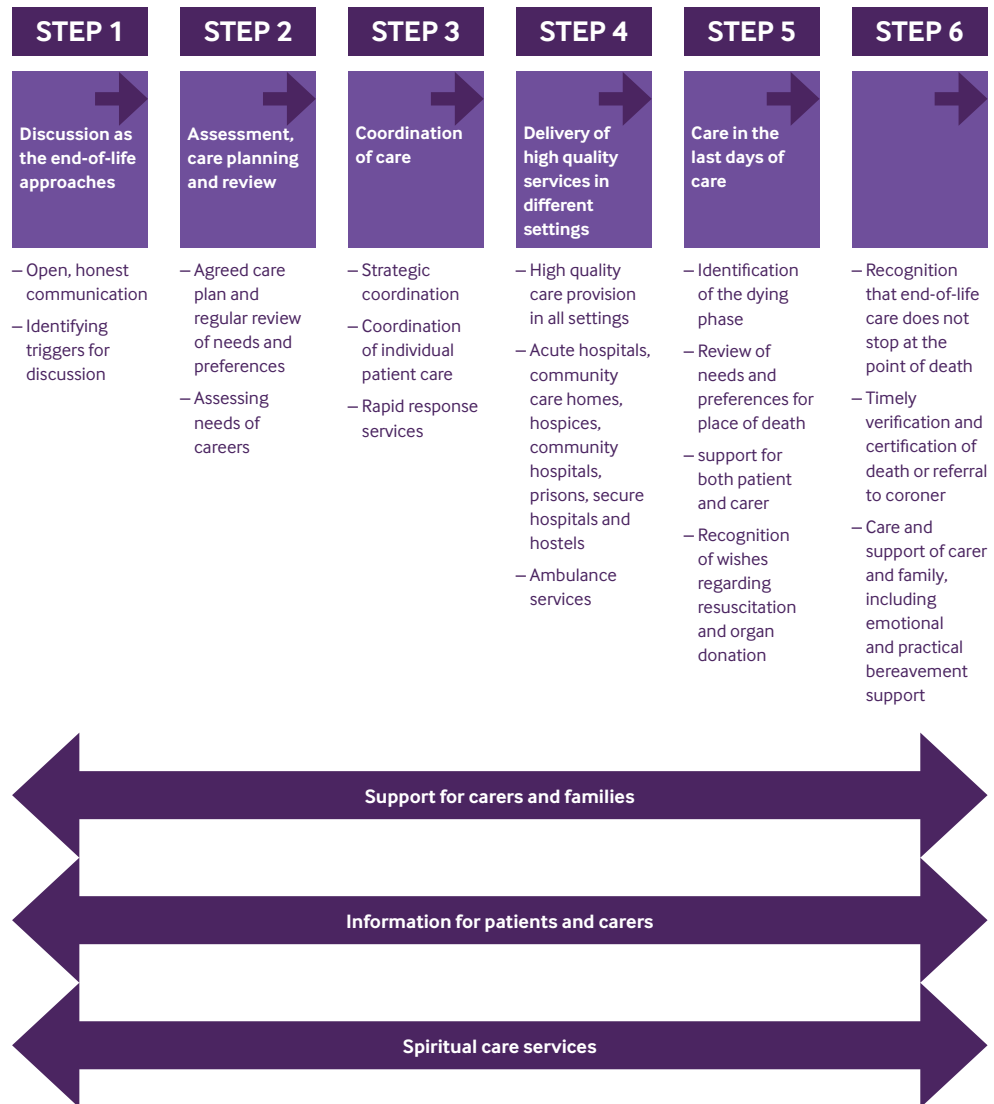


Figure 1 – Taken from Department of Health (2008) *End-of-life Care Strategy: Promoting high quality care for all adults at the end of life*. DH: London. p.49. [Redrawn with permission.]

Most NHS Trusts in England have drawn on the national strategy to create local strategies. This means there is some variance in provision across the nation. A freedom of information request made ahead of the October 2015 debate on the Access to Palliative Care Bill in the House of Lords asked all clinical commissioning groups (CCGs) in England about the level of palliative care services commissioned. It found that expenditure of CCGs ranged from between £15 and £10,504 per patient with palliative care needs, with an average spend of £886 per patient.<sup>24</sup> Seventy-eight per cent of CCGs commission 24/7 specialist palliative care advice services. Only 29 per cent knew how many people in their area had palliative care needs.

The 2008 strategy also involved additional funding commitments designed to double the investment in palliative care, including a range of actions to support people to die at home; raise public awareness of end-of-life issues; and promote workforce development.

The strategy advocated a 'whole system approach' – an approach without restrictive service boundaries, and which encourages the participation and contribution of all relevant teams – and within this, a care pathway approach for commissioning services and delivering integrated care for individuals.

One year on from the publication of *One Chance to Get it Right*, which set out the approach health and care organisations and staff caring for dying people should adopt following the end of the use of the Liverpool Care Pathway, the Department of Health released a report, which noted the following progress:<sup>25</sup>

- The Care Quality Commission (CQC) has finalised and implemented a new inspection approach to incorporate the priorities for care.
- Professional regulators have met, or are in the process of meeting, with regard to updating codes of conduct, improving education and training requirements and curricula, and raising awareness of end-of-life care in general.
- The National Institute for Health and Care Excellence (NICE) has made good progress in preparing best practice guidance for high quality and compassionate hospital care for people who are dying. The consultation on this guidance closed in September 2015, and at the time of writing, the guidance was expected to be published before the end of 2015. Current NICE guidance on the care of adults at the end of life was published in November 2011, and updated to take account of the phasing out of the Liverpool Care Pathway in 2013.<sup>26</sup>
- The National Institute for Health Research has completed a number of research projects in end-of-life care, and has issued calls for new research in this area.
- The Department of Health has completed work on updating the Mandate to the NHS and on the role of named responsible clinicians, who would have the overall responsibility for the coordination and continuity of a patient's care during their hospital stay.

#### **Parliamentary concerns**

In 2015, the House of Commons Health Committee examined the way that health and social care services (including the voluntary and community sector) support people who are likely to die within 12 months, as well as the opportunities for better integration of care services and improving quality of care. The report was published in March 2015 and made various recommendations, including:

- The implementation of a senior named person in each NHS trust to be responsible for monitoring the delivery of end-of-life care;
- The provision of round-the-clock access to specialist palliative care services, including specialist outreach teams;
- The provision of training and support for generalist staff in acute settings in identifying people at the end of life;
- Equity of access to end-of-life care for dementia patients;
- The provision of training in advance care planning for all staff who provide palliative and end-of-life care;
- Encouragement and monitoring the take-up of electronic care planning and Electronic Palliative Care Coordination Systems (EPaCCS), in order to facilitate information sharing between providers and explore options for a universal system for recording and filing advance care plans, with a standard template for use across England and a website dedicated to explaining the issues;
- Prioritisation of end-of-life care by the Department of Health and NHS England, which should ensure that it is embedded in future planning at all levels. They should identify named individuals who will be responsible for ensuring that the new approach to end-of-life care, based on the five priorities identified by the Neuberger Review, is delivered nationally.

In England, the Government's *Five Year Forward View* will continue to dictate how healthcare services are designed and delivered.<sup>27</sup> The *Five Year Forward View* document refers specifically to cancer care, and a desire to ensure that cancer services and care are increasingly provided in the community. More generally, the new care models prioritised by the *Five Year Forward View* – in particular, the expansion and strengthening of primary and 'out of hospital' care – may have a significant impact on the way that end-of-life care is provided in the future.

In September 2015 the Parliamentary and Health Service Ombudsman published *Dying without Dignity*, a report to Parliament on complaints received about end of life care in England.<sup>28</sup> Complaints fell into six key systemic areas:

- Not recognising that people are dying, and not responding to their needs – if the needs of those who are close to death are not recognised, their care cannot be planned or coordinated, which means more crises and distress for the person and their family and carers.
- Poor symptom control – people have watched their loved ones dying in pain or in an agitated state because their symptoms have been ineffectively or poorly managed.
- Poor communication – healthcare professionals do not always have the open and honest conversations with family members and carers that are necessary for them to understand the severity of the situation, and the subsequent choices they will have to make.
- Inadequate out-of-hours services – people who are dying and their carers suffer because of the difficulties in getting palliative care outside normal working hours.
- Poor care planning – a failure to plan adequately often leads to the lack of coordinated care, for example, GPs and hospitals can fail to liaise.
- Delays in diagnosis and referrals for treatment – this can mean that people are denied the chance to plan for the end of their life and for their final wishes to be met.

Following this, the House of Commons Public Administration and Constitutional Affairs Select Committee published a response to the PHSO, following its own inquiry.<sup>29</sup> The Committee welcomed the PHSO report to Parliament and outlined the key areas requiring significant and fast-paced improvements: culture, behaviour and training; the provision of integrated, 24/7 palliative and end-of-life care services; and leadership and commissioning. It also invited the Government to set out how it will ensure that the necessary improvements to end of life care provision are delivered.

At the same time, the National Palliative and End of Life Care Partnership, a large group of national organisations responsible for end of life care (including NHS England, the Association for Palliative Medicine, Marie Curie, the Care Quality Commission, Royal Colleges, Health Education England, Sue Ryder, the National Council for Palliative Care and many others) published *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020*, which sets a framework of actions aimed to improve the consistency and quality of end of life care.<sup>30</sup> The aims are grouped around six main themes:

1. Each person is seen as an individual;
2. Each person gets fair access to care;
3. Maximising comfort and wellbeing;
4. Care is coordinated to get the right help at the right time from the right people;
5. All staff are prepared to care;
6. Each community is prepared to help.

In September 2015, Public Health England and NHS England announced the implementation of a new data collection system from adult specialist palliative care services in England.<sup>31</sup> The new data collection is due to start in July 2016, and is being implemented with the aim of improving outcomes for patients, carers and their families, and to support the development of a new funding model by NHS England.

In October 2015 the Care Quality Commission rated over 90% of the 37 hospices it had inspected in England as 'outstanding' or 'good'.<sup>32</sup> There is general recognition, however, that the availability of high quality palliative care is variable, both between different parts of the country and between healthcare establishments. At the time of writing a private member's bill, the Access to Palliative Care Bill, was under consideration in the House of Lords. This Bill makes provision for equitable access to palliative care services in England by placing a duty on clinical commissioning groups (CCGs) to ensure that specialist palliative care services are available to all those who need them.<sup>33</sup>

Specifically, it would require clinical commissioning groups to make arrangements to ensure that the following services are available to people with palliative care needs:

- (a) 'Support to people with complex palliative care needs in their own homes, in hospitals, in hospices, in care homes and elsewhere within the local community;
- (b) Direct admission of people with palliative care needs to hospice beds, including on an urgent basis when reasonably required;
- (c) Support to other health and social care providers who are caring for people with palliative care needs;
- (d) Specialist palliative care and hospice services which are available on every day of the week;
- (e) Sufficient specialist professionals who are available to deliver services to meet all reasonable requirements;
- (f) Sufficient equipment for any specialist professionals to enable the delivery of services to meet all reasonable requirements;
- (g) Telephone advice from a healthcare professional who is qualified as a specialist in palliative care which is available at all times to professionals providing care to people with palliative care needs;
- (h) Facilities to enable healthcare professionals to access essential medication at all times for palliative care patients being cared for in their own homes;
- (i) A point of contact which is available at all times for people with palliative care needs who are being cared for in their own home or usual place of residence, and those important to them, in the event that such persons are unable to access their usual sources of support; and
- (j) Appropriate systems to ensure that appropriate information about people who have palliative care needs can be made available with the consent of the person to relevant health and social care providers and to the ambulance services'.<sup>34</sup>

The Bill would also require Health Education England to ensure that all health professionals are trained in:

- (a) 'The importance of pain control and that neglect of a person's analgesic requirements can be a failure of a duty of care;
- (b) Communication skills to be able to offer discussion about a person's needs and preferences;
- (c) The importance of the Mental Capacity Act 2005 with relation to people with palliative care needs;
- (d) Ways to support families and carers (including children and vulnerable adults) of people with palliative care needs, to involve them in appropriate decision making and provide practical and emotional support during bereavement'.<sup>35</sup>

The Bill received its Second Reading on 23 October, where it received significant support from peers and progressed to Committee Stage.

## 2. Wales

Wales has a population of just over 3 million.<sup>36</sup> Around 627,000 people are aged 65 or over and around 81,000 are aged 85 or over.<sup>37</sup> Around 32,000 people die each year, which equates to 87 people a day.<sup>38</sup> Of those, around 250 are children and young people, and over 20,000 (almost two thirds) are aged 75 and over. The majority of deaths follow a period of chronic illness such as heart disease, cancer, stroke, respiratory disease or neurological disease.<sup>39</sup>

In Wales, the provision of end-of-life care is governed by *Together for Health – Delivering End-of-life Care*, which was published by the Welsh Government in 2013.<sup>40</sup> This emerged from the 2007 coalition government's programme for Wales entitled *One Wales – A Progressive Agenda for the Government of Wales*, which endorsed the principle that, in building a world-class health service, care should be available to everyone, regardless of who they are or where they live in Wales.<sup>41</sup> There was substantial evidence to suggest that this was not the case in end-of-life and palliative care, and a Palliative Care Implementation Board was formed under Professor the Baroness Iloria Finlay to identify the particular challenges facing palliative care services. Its report, *Dying Well Matters*, was published in 2011<sup>42</sup> and

contained a number of recommendations on how to improve end-of-life care for all, which were incorporated in the 2013 *Together for Health* strategy.

The key aims of the *Together for Health* delivery plan include providing 24/7 support to all people entering the terminal phase of their illness and ensuring pain and symptoms are controlled. It states that access to appropriate support and symptom control must be the same wherever a person dies – at home, in hospital, in a care home or a hospice. The plan also stresses that those who wish to be cared for, and to die, at home, should be supported in this choice.

Importantly, the delivery plan provides a framework for local health boards and NHS trusts for the delivery of accessible, high quality, end-of-life care. Local health boards are required to produce and publish detailed local end-of-life care delivery plans to identify, monitor and evaluate action needed. The local health board executive leads for end-of-life care report progress formally to their boards against milestones in these delivery plans, and publish these reports on their websites.

The plan also identifies areas where improved outcomes are required, including supporting people in Wales to have a healthy, realistic approach to dying and to make arrangements in advance for the end of life; detecting and identifying patients with palliative care needs as early as possible; and improving patient access to information to help them make decisions about their care and treatment. The delivery plan also develops education programmes for general practitioners and educational initiatives for nursing homes. A palliative care module has been established from the computerised clinical database, Cancer Network Information System Cymru (CaNISC), for use by all specialist palliative care teams as a clinical database. Welsh Quality Markers for service provision have been developed with Health Inspectorate Wales to form the basis of a peer review programme.

CaNISC has also had a palliative section developed for inclusion, which is used by all specialist palliative care providers to register patient contacts, allowing round the clock access to clinical records and ensuring that data are collected in a standard format, which allows meaningful benchmarking of services.<sup>43</sup>

The delivery plan is supported by a number of other initiatives. Patient feedback is collected on a regular basis and reported monthly for each team across Wales, primarily through iWantGreatCare (iWGC)<sup>44</sup> and Dying Well Matters (DWM),<sup>45</sup> which were put in place to ensure services are receptive to patient need in the long term. The *Byw Nawr* (Live Now) initiative, was established in September 2014, and aims for people in Wales to feel comfortable talking about dying by encouraging them to engage in conversations and activities that promote a healthy and realistic attitude to death and dying.<sup>46</sup>

The Welsh Government continues to publish annual reports which track how well it is performing against the outcomes set out in the delivery plan. The reports bring together national and local level information about end-of-life services.<sup>47</sup> The 2014 annual report indicated a number of positive aspects of the implementation of the delivery plan, including the fact that 80 per cent of urgent specialist palliative care referrals were assessed within the agreed timescale. However, the report also identified a number of areas which required improvement, including earlier identification of patients who are probably in their last year of life, so they can receive earlier support; ensuring that systems are in place to allow more people to receive care and die in a place of their choice; and reducing unnecessary emergency admissions for those at the end of their lives through effective advanced care planning.



### 3. Scotland

The total population of Scotland is around 5.3 million.<sup>48</sup> Around 970,000 people are aged 65 or over and around 119,000 are aged 85 or over.<sup>49</sup> Over 54,000 people die in Scotland each year.<sup>50</sup>

In 2008 the Scottish Government published *Living and Dying Well: a national action plan for palliative and end-of-life care in Scotland*, which sets out the strategic focus required to improve end-of-life and palliative care services across Scotland.<sup>51</sup> It emphasises a person-centred approach to care and care planning and the importance of communication, collaboration and continuity of care across all sectors at all stages of the patient journey. The strategy describes end-of-life and palliative care as integral aspects of any care delivered by health or social care professionals, focussing on the person, not the disease, and applying a holistic approach to meet the physical, social, emotional and spiritual needs of patients and their carers facing progressive illness and bereavement. The Government identified the importance of NHS Boards working with key stakeholders, including the voluntary sector and social care partners, in order to deliver high quality end-of-life care. Therefore, as part of the delivery of this strategy, the Government appointed a National Clinical Lead for Palliative Care and each NHS health board has an Executive Lead in place.

The strategy sets out a clear action plan to enable all health boards in Scotland to plan and develop services that would embed a cohesive and equitable approach to the delivery of end-of-life care for patients and families living with and dying from any advanced, progressive or incurable condition across all care settings in Scotland. The main areas for action were identified as the assessment and review of palliative and end-of-life needs; planning and delivery of care for patients with palliative and end-of-life needs; communication and coordination; and education, training, and workforce development.

The strategy recognises the importance of communication between professionals and patients and their families and carers in all settings where palliative care is delivered. However, it also recognises the challenges of ensuring effective communication and coordination between professionals and across organisational boundaries, systems and structures. The strategy therefore includes a key action to identify a named health or social care professional to plan and coordinate care, who will ensure that timely and relevant information is communicated to all other professionals involved, particularly during transition between settings.

A progress report on the strategy was published in 2012<sup>52</sup> and reported that a number of key actions set out in the original strategy had been either fully or nearly achieved on a consistent basis across Scotland, including:

- The development of ePCS (Electronic Palliative Care Summary) to support the sharing of vital clinical information across care settings;
- Improvements in palliative care in care homes through educational support from hospices and NHS boards;
- Agreement of national referral criteria for specialist palliative care;
- The development of national clinical guidelines to support the practice of generalists;<sup>53</sup>
- The development and piloting of a Structured Scottish Response (SSR) to the care of patients in hospital whose condition is deteriorating and whose recovery is uncertain, which prompts appropriate communication and planning with patient and family;
- Improvements in professional knowledge and awareness of care in the last days and hours;
- The development of local services directories and the creation of a dedicated information resource on the NHS Inform portal.<sup>54</sup>

Following similar discussions to those in England on the Liverpool Care Pathway, in December 2013 the Scottish Government announced its intention to phase out the LCP. A year later, it published guidance *Caring for people in the last days and hours of life*, which set out the following four principles to be used as the framework to support continuous planning, development and improvement at a local level across health and social care settings in Scotland:<sup>55</sup>

1. Informative, timely and sensitive communication is an essential component of each individual person's care.
2. Significant decisions about a person's care, including diagnosing dying, are made on the basis of multi-disciplinary discussions.
3. Each individual person's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible.
4. Consideration is given to the wellbeing of relatives or carers attending the person.

Building on the positive work that has taken place so far, the Scottish Government is committed to the development of a Strategic Framework for Action, to maintain momentum and to further support the delivery of high quality palliative care across all healthcare settings.<sup>56</sup> At the time of writing, this piece of work was ongoing and due to be published before the end of 2015. Throughout 2015, the Health and Sport Committee held an inquiry into Palliative Care in Scotland, and published its report *We need to talk about Palliative Care* in November 2015.<sup>57</sup> The report highlighted concerns around access to specialist palliative care services, particularly for those with conditions other than cancer, the homeless, and those with learning difficulties and concluded that all patients should have a right to end-of-life care regardless of where they live, their age, and their condition. The report also noted the need for training for doctors in initiating conversations around death and dying. They called on the Government to address these issues in the Strategic Framework for Action.

#### 4. Northern Ireland

Northern Ireland has the smallest population of all the nations, at 1.8million.<sup>58</sup> Around 293,000 people are aged 65 or over, and 36,000 are aged 85 or over.<sup>59</sup> In 2014, 14,678 deaths were registered in Northern Ireland. Of those, cancer amounted for the highest number of all deaths (29%), followed by circulatory diseases (25% of all deaths) and respiratory diseases (14% of all deaths).<sup>60</sup> Sixty-four per cent (64%) were people aged 75 and over, and a further 23 per cent were people aged 60 to 74. The number of deaths due to Alzheimer's and other dementias increased by 6.8 per cent on the previous year.<sup>61</sup>

The main end-of-life care strategy for Northern Ireland is *Living Matters, Dying Matters: A palliative and end-of-life care strategy for adults in Northern Ireland*, which was published in March 2010.<sup>62</sup>

The strategy spanned a period of five years (2010-2015) and contained 25 recommendations. Building upon a number of existing policies and guidelines which have directly and indirectly contributed to the development of palliative and end-of-life care services in Northern Ireland, it advocated a person-centred, holistic approach to the planning, coordination and delivery of high quality reliable care which would enable patients to retain control, dignity, and choice in how and where their care is delivered towards the end of their lives.<sup>63</sup>

The strategy further recommended that essential medical and nursing services should be further developed and accessible in the community on a 24/7 basis for all who need them, including access to medication and pharmacy services; access to equipment; and access to specialist palliative care teams.<sup>64</sup>

The Public Health Agency led in the implementation of the strategy. It, along with the Health and Social Care Board and Marie Curie, took forward the *Transforming Your Palliative and End-of-life Care Programme* which complemented the strategic direction set out in the strategy in the form of a Model for Palliative and End-of-Life Care as a vehicle for delivering high quality care:-<sup>65</sup>

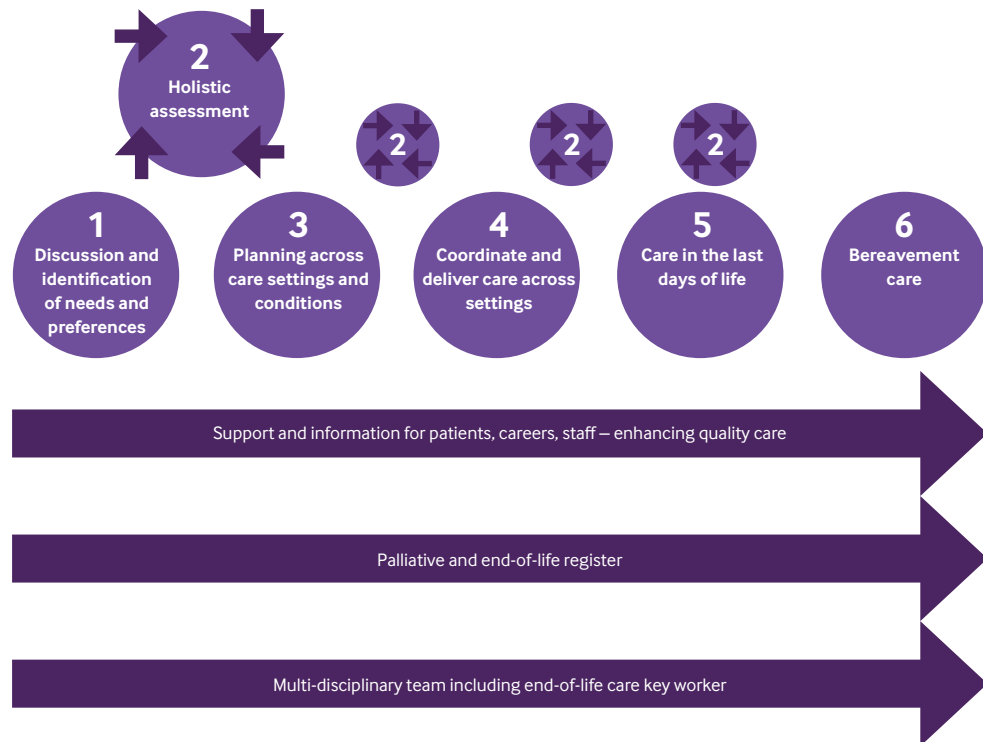


Figure 2 – Taken from DHSSPSNI (2010) *Living Matters, Dying Matters: A palliative and end-of-life strategy for adults in Northern Ireland*. DHSSPSNI: Belfast. p.25. [Redrawn with permission.]

This model enables the discussion and identification of patient, family and carer needs through continuous holistic assessment and recognises how patient choice needs to be supported by appropriate infrastructures and services, including 24 hour access to essential services.

The model also allows for the role of the end-of-life key worker, an identified individual with responsibility for planning and coordinating patient care across interfaces, promoting continuity of care and ensuring that the patient and health and social care staff know how to access information and advice.

As the time span for *Living Matters, Dying Matters* was coming to an end in 2015, the then Health Minister Jim Wells informed the Northern Ireland Assembly that the potential for service re-design would be considered in the coming months.<sup>66</sup>

The Northern Ireland strategy is supplemented by a number of other public policy initiatives and service frameworks. *Transforming Your Care* (TYC) sets out an “overarching road map for change in the provision of health and social care services in Northern Ireland”. Its main thrust is care at the right place and at the right time, with an emphasis on care close to home, and this applies equally to the provision of end-of-life and palliative care. The report published in December 2011<sup>67</sup> identified the following proposals for the provision of end-of-life and palliative care:

- Development of a palliative and end-of-life care register to enable speedy transfer of information required by those providing care;
- Enhanced support to the nursing home sector for end-of-life care;
- Individual assessment, planning, delivery and coordination of end-of-life care needs by a key worker;

- Electronic patient records in place for the patient, their family and staff;
- Targets to reduce the level of inappropriate admissions for people in the dying phase of an illness.

The palliative and end-of-life aspects of *Transforming Your Care* are currently being taken forward by the Health and Social Care Board and Public Health Agency in conjunction with Marie Curie and a range of statutory, voluntary and independent sector partners. The programme aims to improve the design and delivery of coordinated services and ensure equity of access to services for both urban and rural communities, and has identified various work-streams which seek to improve how palliative and end-of-life care is delivered, including support for patients and carers; enhanced access to care services at home; and identification and planning for people with palliative care needs.<sup>68</sup>

The Health and Social Care Board has also been working with Integrated Care Partnerships (ICPs) to put in place new care pathway arrangements for patients who are frail and elderly, have had a stroke, or who have diabetes or chronic respiratory conditions. These new pathways will support people to be cared for at home at the end of their life.<sup>69</sup> The ICPs will also provide support to GPs in advance care planning and training on palliative and end-of-life care, and will give consideration to the role of community pharmacy in supporting palliative care, including urgent out-of-hours response.<sup>70</sup>

Service Frameworks have only recently been developed across a number of clinical areas in Northern Ireland. All Service Frameworks incorporate a specific set of generic standards which are intended to apply to all service users and all health and social care professionals, regardless of their health condition or social grouping. The relevant service frameworks that have been finalised all have the following generic palliative and end-of-life standard: "All people with advanced progressive incurable conditions, in conjunction with their carers, should be supported to have their end-of-life care needs expressed and to die in their preferred place of care".<sup>71</sup> More detailed standards for end-of-life and palliative care are included within the Service Frameworks for Cancer Services,<sup>72</sup> Learning Disabilities,<sup>73</sup> and Older People.<sup>74</sup>

## 5. Funding

### State funding

Funding for end-of-life and palliative care is complex, with some services being commissioned and paid for through the NHS, and others supported through voluntary sector funding. It is difficult to calculate the exact costs of end-of-life care, due to the fact that many services are provided in the community, and so are not distinguished from other generalist care.

In 2011 the Palliative Care Funding Review published its report on funding for palliative care in England and drew attention to the "stunning lack" of good data on the costs of palliative care.<sup>75</sup> The review noted the wide variation in the level of state funding provided to services, estimating at the time of writing that primary care trusts (PCTs – now clinical commissioning groups or CCGs) spent £460 million on adult end-of-life and palliative care. The variation between trusts was stark, with one PCT spending about £0.2 million on specialist palliative care, whilst another spent about £21 million.

In March 2015 NHS England published a new approach to palliative care funding using the 'palliative care development currency'.<sup>76</sup> The palliative care currency is a set of commonly provided units of care based on patient need at the end of life. It takes into account everything that is involved in the provision of care for that period of time. The currency is not condition-based but provides a 'unit' for all conditions and is based on set criteria, including whether a patient is stable, unstable, deteriorating or dying; is older or younger than 75 years of age; has more than one diagnosis; care setting - whether the patient is an acute inpatient, a hospice inpatient or in community care; and whether the patient has low, medium or high functionality.

NHS England is attempting to identify currency units that can be implemented across England for all organisations providing specialist palliative care (for both adults and children). These units will be monitored by organisations (which volunteer to take part) throughout 2015-16 to look at the actual price associated with the unit. Unit price will be based at a local level and could inform development of a national unit price. NHS England has been explicit in stating that the currency will not be mandatory for 2015-16.

The Welsh model for funding uses a formula to distribute central funds for palliative care to various areas and services across Wales. In August 2014, Health Minister Mark Drakeford announced a £6.4 million funding package to support hospices and provide palliative care across Wales.<sup>77</sup> The funding was made available for hospices and health boards in 2014-15 to provide specialist consultants, nurses, and other health support for palliative care.

When considering a Palliative Care (Scotland) Bill in 2010, the Scottish Government noted that it was very difficult to provide a figure for the amount of funding that went to generalist palliative care settings, due to both the lack of ring-fenced funding to deliver it, and the fact that data on the cost of general palliative care are not collected at a local or national level. Through a survey of NHS Boards and hospices, however, it was found that £59 million was spent on specialist palliative care in 2006-7 – 56 per cent of which came from the state.<sup>78</sup> It has been suggested – most recently in the Economist Intelligence Unit's 2015 report on palliative care – that the provision of timely palliative care has the potential to reduce other healthcare costs, for example, by reducing admissions to hospital or hospital stays post-admission.<sup>79</sup>

### **Voluntary sector**

A substantial proportion of end-of-life care is provided by voluntary sector organisations. This care may be provided in charitably-funded hospices, through funded staff in local hospitals, and nursing and medical care within the community. Whilst hospices receive some funding from the state, it does not normally cover their full clinical running costs. In 2007, the Royal College of Physicians warned that the reliance on charitable funding and provision has created many of the problems associated with the accessibility of end-of-life care, and “exacerbates inequalities, favours the model of stand-alone hospice buildings and has led to poor planning and overall integration of services”.<sup>80</sup>

The actual percentage of state funding for hospices varies considerably around the country, from on average 19 per cent in Wales to 39 per cent in Scotland in 2013.<sup>81</sup> Even within the nations, the amount received by each hospice varies considerably. In England, for example, several hospices received less than 20 per cent funding from the government, while at the other extreme some received more than 50 per cent funding.<sup>82</sup> An earlier census of independent hospices in England found that 97 per cent of hospices did not feel the funding they received from the NHS was adequate to cover the costs of the NHS services they provided.<sup>83</sup> Wales, Scotland and Northern Ireland experience similar funding arrangements, whereby a large proportion of specialist palliative care services are provided, and funded, by voluntary organisations. Hospices in Northern Ireland, for example, receive around 31 per cent of their costs from the Government.<sup>84</sup>

Under the guidance set out in a 2003 Health Department letter, NHS Boards in Scotland are required to fund 50 per cent of the agreed annual running costs of independent voluntary hospices providing specialist palliative care services in their area.<sup>85</sup> This was confirmed by a later letter from the Scottish Government in 2012.<sup>86</sup> A 2008 report from Audit Scotland found that in reality NHS Health Boards funded between 41 per cent and 53 per cent of the costs of voluntary hospices.<sup>87</sup> It concluded that whilst commissioning arrangements were improving, there were still differences of opinion between NHS Health Boards and hospices as to what should be funded.

### Social care

Care at the end of life does not only involve healthcare. In addition, people may need social care at the end of life. Different funding arrangements and rules apply across the country. In Scotland, for example, there is a legal entitlement to free personal care for all people aged 65 or over who have been assessed as having a need; and to free nursing care for people of all ages assessed as requiring nursing services.<sup>88</sup> Social care in Northern Ireland is also provided free in the patient's own home.<sup>89</sup>

Elsewhere, whilst NHS provided care is free, the costs of other social care required may need to be met by the patient and their families. Some social care provided by local authorities may be means tested, although the costs, plus the assessment, vary across local authorities.

Marie Curie, along with five other national charities, is campaigning to ensure that social care is provided free of charge for those who are terminally ill. The Health Select Committee report into end-of-life care also stated that social care should be free at the end of life.<sup>90</sup> In its response the Government said that it was working to remove barriers in the current social care system and that providing free social care was just one of many possible solutions to ensure that more people are able to access the support and care they need at the end of life.<sup>91</sup>

### Part Three – End-of-life care in hospital settings

Although most patients report that they would prefer to be cared for and die in their own home or in a hospice, vast numbers are admitted to hospital in the final stages of their life, and many will die there. In Wales in 2012, emergency and elective hospital admissions in the last year of life accounted for more than one million bed days – nearly a quarter (23.8%) of all hospital bed days.<sup>92</sup> In Scotland, it has been estimated that 1 in 3 patients in hospital are in the last year of their life, highlighting the need for more work to be done in order to recognise when patients are nearing the end of their lives and to provide appropriate care accordingly.<sup>93</sup>

The provision of services in hospital settings varies greatly. In some places specialist palliative care teams provide round-the-clock support and are well integrated with other hospital teams, and with social and community services. A national audit conducted by the Royal College of Physicians and Marie Curie showed, however, that less than a quarter of hospitals in England provided face-to-face palliative services 7 days per week.<sup>94</sup>

## 6. Health professionals' perceptions of end-of-life care in hospital settings

A number of studies have explored the perceptions of palliative care provision in this setting amongst both hospital workers and those in primary care.

Reid *et al* explored healthcare professionals' views on delivering end-of-life care in an acute hospital trust in the South West of England.<sup>95</sup> The study comprised six focus groups, seven in-depth interviews and five "questerviews" involving a range of different healthcare professionals. The participants reported on issues to do with the provision of palliative care across three main themes, the diagnosis of death, cultural issues and structural factors.

The study found that hospital staff reported difficulties in recognising when a patient was dying, with recognition being "very late and sometimes within hours of death".<sup>96</sup> Reasons included lack of familiarity with the patient if seen out of hours and lack of experience in recognising impending death. There was also disagreement amongst members of staff about who should make the diagnosis – nurses looked to doctors for confirmation whereas, for doctors, nursing staff were best placed to do this as they had spent more time observing a patient. The cultural issues identified by staff included the tendency to regard the active treatment of patients as always in their best interests and not acknowledge dying; some participants also referred to the decision to recognise dying in terms of "bravery". Other cultural issues included the different attitudes to end-of-life care amongst different consultants which could affect the decision making of junior doctors, while some respondents stated that junior doctors could sometimes be anxious in prescribing medications used at the end of life, leading to delays in symptom control. A number of

structural factors were identified as problematic in the provision of palliative care, including the impact of shift patterns and the documentation of care provided by different teams, leading to uncertainty about changing to comfort care or the frequency of review from senior doctors when validation of the diagnosis of dying was needed by junior doctors. A final structural impact was pressures on beds which meant that continuity of care was affected because “patients are shuffled between wards”. The lack of availability of single rooms, which give dying patients privacy, was also identified as an issue which distressed staff, who would try and move patients to quieter parts of the wards. Staff reported that private rooms were often prioritised for patients who posed an infection risk.

Many of these issues, and some of the participants’ specific comments, were echoed in an earlier qualitative study into palliative care in acute settings. Two studies published in 2011 used focus groups and individual interviews with 58 health professionals in hospitals, GP surgeries and hospices in Sheffield and Lancaster to investigate the transitions to palliative care in acute hospitals,<sup>97</sup> and the barriers that exist specifically in relation to the care of older people in this setting (discussed in more detail below).<sup>98</sup>

Gott *et al* looked at how the change in focus in the goals of a patient’s care from active treatment to maximising quality of life was managed. Like the findings from the research described above, the authors found that “structured transitions to a palliative care approach early in the patient’s disease trajectory” rarely happened in the hospital setting and the focus on acute medicine was cited as one of the reasons by participants. Discussion about prognosis with patients and their families was also “not routine” according to all participants, “representing a key barrier to a structured transition to a palliative care approach being initiated”. The authors found that transitions to palliative care happened close to death, with potential implications for end-of-life care preferences. A phased transition between the two forms of care, active and palliative, was also “rarely evident in the hospital setting, apart from among patients with cancer receiving palliative chemotherapy”. Instead, some participants identified there to be an “either/or mentality”.

Gott *et al* also found that communication was identified to be important in decision making, but respondents identified a number of different issues. The decision to make the transition to palliative care was seen as “challenging” by one of the doctor participants and, similar to the study above, it was described as “taking courage” by a nurse in the study. Primary care professionals who took part in the focus groups for the research also confirmed that there were barriers to the communication of information from secondary to primary care, with hospital clinicians failing to tell patients they now needed palliative care, giving them a false hope of cure. There was also some disagreement over who was best placed, hospital doctors or GPs, to communicate that the change in focus was now required.

Some of the general points raised in these studies were also highlighted in a study published in 2014, which looked specifically at the perceptions towards palliative care of eight specialty registrars and consultant haematologists in the West Midlands.<sup>99</sup> Participants reported positive experiences with palliative care but identified issues with variable service provision and difficulties in referring patients to local hospices for inpatient care. The timing of palliative care was seen as a challenge because of the sometimes relapsing and remitting nature of the disease trajectory. This also impacted on the referral of patients, with participants uncomfortable about doing so where there was a chance, even if relatively low, that patients would be cured. There was also a concern that referring at diagnosis could lead to patients being overwhelmed or confused because of conflicting information. Making the decision to transition from curative treatment to palliative care and referral to palliative care services was also seen to be difficult and was identified with failing a patient. This was linked to the more intense and protected doctor-patient relationship compared with other specialties and a desire for control over the disease outcome. Patient expectations and hopes added pressure in this regard.

## 7. End-of-life care for older people in acute settings

The specific barriers to providing palliative care to older patients include a perception amongst some staff that, although high numbers of older inpatients in acute hospital settings have palliative care needs, there were different understandings of whose responsibility it was to address these. Some geriatrician respondents, for example, were uncertain about their claim to expertise in this area and whether it was a core part of the role.<sup>100</sup> Palliative medicine specialists believed basic palliative care could and should be part of everyone's role. This study also highlighted a perception that older people required less palliative care than younger people, a consequence of death being "expected" in older people, and the perception that older people find it easier to come to terms with death. The limited social or family support that might be available to them could act as barriers to the provision of appropriate care. Again resources were perceived to be an issue, with older patients with non-malignant illness less likely to be referred to specialist services, in part because of the historic link between cancer and palliative care, and with inadequate staffing and time pressures on generalists, impacting on their ability to provide good palliative care.

## 8. Optimum environment for end-of-life care in hospitals

The physical environment in which care takes place can have a significant impact on outcomes and physical and psychological wellbeing. One study therefore looked at the optimum environment for palliative care in hospitals.<sup>101</sup> Hospices are generally regarded to be a superior setting in which patients can receive care at the end of life, but only a proportion of cancer patients and a minority of patients with non-malignant diseases receive hospice care. Although the importance of providing appropriate environmental conditions was acknowledged by participants in the focus groups in this study, they were also unsure how or whether considerations like homeliness could or should be provided in hospital settings. Issues included the strict regulations and requirements for providing high quality clinical care and infection control. Resource issues were also identified in providing facilities for families, to stay overnight for example, or for the bereaved, when time and bed management pressures could impact on the time available for families to spend time with their relative after he or she has died. There was consensus that it was important to provide appropriate privacy options and allow choice between these for patients, although there was disagreement over whether private rooms – which are quieter, more confidential and allow for the provision of dignity – were best compared to multi-bed accommodation, which some patients may prefer as they provide the opportunity for social interaction.

## Part 4 – End-of-life care in the community

In light of the fact that a large proportion of people express a preference to stay at home at the end of life, the recent end-of-life care strategies developed by each of the four nations focus on the importance of extending generalist care, and of involving specialist palliative care as and when necessary. Since 2008, there has been a marked increase in the number of patients recorded on GP palliative care registers. The extent to which people with a palliative care need are placed on a register varies across the country. In Wales in 2013, for example, 7,152 people were registered on a primary care palliative register, but data from Marie Curie suggest that the majority of those requiring palliative care still remain unrecorded on primary care palliative care registers.<sup>102</sup>

Where patients elect to stay in the community at the end of life, they are likely to be reliant on services delivered by primary care staff, including GPs and district nurses. However, some research shows the role of primary care staff in relation to palliative care can be unclear, and there can be inconsistency and gaps in provision. The continued provision of high quality end-of-life care in the community may be even more challenging in light of future GP shortages and the likely increased pressures on workloads of looking after an ageing population.<sup>103</sup>



## 9. The perceptions of health professionals, patients and carers on end-of-life care in the community

A number of studies have explored some of the challenges and barriers to providing coordinated care across different settings for palliative care patients. As lack of coordination is associated with causing poor quality care and increasing the burden on family carers, Mason *et al*/ used a mixed methods approach – incorporating ethnographic observation and qualitative interviews with staff, patients and carers – to assess how and to what extent coordinated care is conducted in generalist settings.<sup>104</sup> The study was conducted in three separate care settings in different parts of the UK: a Scottish teaching hospital, a Midlands general practice with 11,000 patients across urban and rural areas, and a respiratory outpatient unit in London. The authors found that across all three sites there were problems with coordination, particularly with respect to the exchange of information when patients moved between service providers; that tensions existed between the need for efficiency and the delivery of patient-centred care; and that there was variability of knowledge amongst healthcare staff. Some of the key themes which emerged from the study regarding the coordination of care as set out below:

- The authors found that in “most cases a family carer or the patient took on the primary coordinating role” and that “GPs were sometimes seen to play a key role” but were usually “only consulted for an acute problem”, with patients not wanting to bother a “busy doctor”.
- Participants reported that some hospitals and primary care teams did provide good coordination but the authors found that problems associated with unplanned hospital admissions and discharges, for example, caused frequent problems in coordination.
- The authors found that “professionals universally experienced difficulties in communicating across institutional boundaries and found information sharing to be inconsistent”.
- Problems of coordination were frequently caused simply because it was not recognised that the patient was approaching the end of life resulting in reactive, rather than planned and coordinated, end of life care.

A systematic review of the available research evidence, mainly from the UK and spanning from 1998 to 2012, looked at the views of patients, carers and healthcare professionals on the provision of palliative care for non-cancer patients by primary care providers.<sup>105</sup> The authors found that patients and carers “highly value [primary care providers’] compassionate care, appropriate knowledge and skills, quick responses to urgent needs, and maintenance of the coordination and continuity of care”.<sup>106</sup> Other principal findings of the review included that healthcare professionals acknowledged there were unclear boundaries between the roles and responsibilities of different professionals. While GPs were seen to play a key role, they reported “juggling competing priorities with a limited amount of time” and expected nurses to take a more active role. Additional barriers to palliative care for non-cancer patients included the unpredictability of illness trajectory which caused uncertainty; resource availability; and primary care providers’ lack of expertise.

Some of the points raised in the studies on coordination of care described above have also been highlighted in research which focussed specifically on the views of GPs. A 2012 study involving eight GPs in both urban and semi-rural practices in South Wales, who had recent experience of managing patients at the end of life, looked at issues around defining palliative care patients and their inclusion on a palliative care register as per the Gold Standards Framework.<sup>107</sup> The research found that defining a patient as in need of palliative care was seen as more of an ongoing process involving the multi-disciplinary team, rather than a decision relating to a specific moment. As a result, inclusion on a palliative care register was shown to follow no “fixed rules”, with patients recorded as in need of palliative care on the basis of need for increased multidisciplinary input rather than their diagnosis. There was agreement that patients with non-malignant diseases had similar needs to cancer patients but because they often had a prolonged period of illness, identifying the palliative phase was more challenging, an issue which impacted on register inclusion. The study participants also cited the advantages of having a register and holding regular meetings, in order to identify potential palliative care patients, coordinate care and communicate with out-of-hours services.

## 10. Out-of-hours care

Out-of-hours care for patients in the last year of their lives is an essential part of palliative care in the community. It has been estimated in the past that patients with cancer, for example, spend 90 per cent of the last year of their lives at home and two-thirds of this falls within out-of-hours periods.<sup>108</sup> A postal survey published in 2014 sought to explore the views, confidence and educational needs of GPs employed by an independent provider of out-of-hours services.<sup>109</sup> Out of 1,005 GPs, 203 responded to the study. The results highlighted that organisational factors, particularly lack of familiarity, time pressures and lack of information from in-hours services, had a greater impact on care delivery than clinical factors. The factors that were ranked lowest amongst respondents were confidence in assessing palliative care emergencies (42.8%), managing symptoms in non-cancer patients (39.4%) and prescribing a new syringe driver (39%).

Two articles report the findings of earlier qualitative studies which explored the views of nine doctors in Cardiff on the challenges associated with providing out-of-hours palliative care in their area. In relation to information and communication issues, the GPs interviewed highlighted the constraints within the system of the private service provider; a feeling of being alone and not knowing whom to call for advice; and handover issues.<sup>110</sup> Other factors that were raised included the lack of familiarity with patients compared to in-hours general practice and fears associated with prescribing for palliative care patients.<sup>111</sup>

## Part 5 – End-of-life care needs and preferences

### 11. Overall need

A 2014 study compared various methods for estimating population-based need for palliative care and then refined them to estimate a minimum of 63.03 per cent of all patients need palliative care, with lower and upper mid-range estimates ranging between 69.10 per cent and 81.87 per cent.<sup>112</sup> Other methods of analysis place the palliative care need at 60.28 per cent (using cause of death and symptom prevalence);<sup>113</sup> between 37.01 per cent and 96.61 per cent (using ICD-10 disease classification and hospital data);<sup>114</sup> and at 75 per cent (using percentage of deaths and chronic disease data).<sup>115</sup> However, in one 2012 study only 29 per cent of people who died were recorded as being on the palliative care register before they died.<sup>116</sup>

A review of palliative care services in Scotland estimated that around three quarters of all people who die in Scotland could benefit from a palliative care approach, and that this number will rise as the population ages and more people die with chronic conditions such as cancer, or with dementia and frailty.<sup>117</sup>

A 2014 report showed that out of all people who died in 2012 in Wales, a total of 17.4 per cent accessed specialist palliative care services.<sup>118</sup>

### 12. Identification of need

Part of the problem with the identification of those in need of palliative care may be that the majority of end-of-life care strategies focus on individuals in the very final stages of their life. A number of experts have suggested that more resources should be provided for the start of the process, for early identification of the need for end-of-life care.<sup>119</sup> Whilst providing oral evidence to the House of Commons Health Committee, Professor Sir Mike Richards, Chief Inspector of Hospitals at the Care Quality Commission (CQC), suggested that care providers should maximise each opportunity to recognise the need for palliative care by, for example, when someone enters a hospital as an acute admission, asking the question about the possibility that this person may die in the next year.<sup>120</sup>

One study into the coordination of end-of-life care in generalist settings found that few patients in the study had been formally identified as being appropriate for a palliative care approach, with the exception of people with advanced cancer, who were more likely to be identified as such. Many, but not all, GPs understood palliative care to mean terminal care, and there was a “clear mismatch between policy and guidance around identifying patients systematically for palliative care and the actual practice observed”.<sup>121</sup>

Identification of need is crucial to improving outcomes. Research suggests that early provision of palliative care yields more favourable outcomes and patients live longer – for example, a study of 151 lung cancer patients at Massachusetts General Hospital found that patients who received earlier palliative care had a better quality of life than patients receiving standard care; had fewer depressive symptoms; and had a higher median survival.<sup>122</sup> Similar research is currently being undertaken in the UK.

### 13. Choice

Patient choice is a long-standing principle of medical practice, and every national strategy emphasises the importance of that applying equally to end-of-life care. In February 2015, the Choice in End-of-life Care Programme Board released a report to advise the government on what a national choice offer for end-of-life care should include (within the current legal framework), and the enablers and barriers associated with these choices.<sup>123</sup>

Its report highlighted the importance of offering people in need of end-of-life care choices focussed on what is important to them, and ensuring that they are supported in making those choices and preferences known. Part of this might include every person having a named responsible senior clinician who would have overall responsibility for their care and preferences, and a care coordinator who would be their first point of contact in relation to their care and preferences. They also recommended that an additional £130 million be identified in the next spending review, and be invested in social care and NHS commissioned services to deliver national choice in end-of-life care by April 2020.

Marie Curie recently launched a campaign to change how the UK thinks and talks about terminal illness and end-of-life care, recognising that with a growing number of people dying each year, it is more important than ever for individuals, policy-makers, and health and social care professionals to discuss the type of care and support required by those at the end of life.<sup>124</sup> Its report, published in 2015, emphasises the importance of making sure people can choose where and how they will live towards the end of life, but also the importance of ensuring families and communities are supported to provide those individuals with the care and support they need. They also highlighted the need to eliminate inequities in access to care, so that everyone at the end of life can receive the same quality and ease of access to care, regardless of who they are, where they live, or what their illness is.

### 14. Pain relief

Pain is one of the most commonly expressed fears relating to advanced disease and the dying process. As explored in the section below on views on a “good death”, a preference for a “pain free” death ranks consistently highly in the public’s hopes regarding the end of life. The BMA Board of Science is in the early stages of a major new report that will explore ways of supporting improvements in analgesic use in the context of palliative care and chronic pain, and is intended to provide a framework for future action in this area.

Pain is a highly subjective experience and the International Association for the Study of Pain provides the most widely used definition which emphasises both sensory and emotional experiences as well as *potential* physical damage.<sup>125</sup> It is well documented that the same stimulae (both in clinical practice and in controlled conditions) will result in highly variable expressions of pain symptoms. These can also be affected by fear, anxiety, depression and lack of sleep.<sup>126</sup> The practice of pain medicine is based around well managed or acceptable levels of symptoms, rather than being completely pain free.

Whilst there are treatments, interventions, and expertise available that can help control pain at the end of life,<sup>127</sup> the available evidence indicates that the majority of patients report some pain at the end-of-life, with the prevalence varying between conditions and studies: some reports indicate pain at some point in between 35 and 96 per cent of cancer patients; 34 and 77 per cent of chronic obstructive pulmonary disease patients; and 47 and 50 per cent of those with renal disease.<sup>128</sup> Good care, however, requires that when pain occurs it is responded to appropriately and fast.

Pain can be managed in a variety of different ways, and there are a number of clinical guidelines for doctors which set out considerations to be taken into account when assessing pain and administering pain relief.<sup>129</sup> These guidelines emphasise the importance of good communication with patients, particularly with regard to fears about tolerance and addiction, and to regularly review the pain control. Part of this may include supporting and educating patients about what can be achieved through pain relief and other interventions. Although most pain can be adequately controlled using analgesics, some, particularly cancer pains, are more complex, requiring input from multidisciplinary palliative care teams and other disciplines such as pain medicine (anaesthetics) and clinical oncology. The aim for clinicians should be to manage pain adequately so that patients can continue to function how and when they choose.<sup>130</sup>

There is a range of evidence to show how far pain is adequately controlled at the end of life, which shows a variation depending on the care setting and access to that care. One study of the bereaved relatives of cancer patients found that pain was “completely controlled” in over 70 per cent of patients in hospices; over 60 per cent of patients at home; and in less than half of patients in hospitals.<sup>131</sup> The National Survey of Bereaved People (VOICES) in England – which is explored in more detail below – shows that pain was reported as being relieved “completely, all of the time” most frequently for patients in hospices (64 per cent), and least frequently for those being cared for at home (18 per cent). Two per cent (2%) reported that pain was “not at all” relieved in hospices; significantly more people reported that pain was not relieved at all at home (8%) than for other settings.<sup>132</sup> Problems may arise in obtaining certain medications for use in the home, particularly out-of-hours.

The extent of pain experienced at the end of life is often used as an indicator of quality of care, but some studies have cautioned against automatically assuming this. One study from the US found that less than a quarter of all terminally ill patients receiving pain relief wanted to receive additional pain therapy. Many of those who did not want to increase treatment cited a fear of addiction or adverse side effects – including constipation, nausea, or mental confusion – as the reasoning behind their decision.<sup>133</sup> The authors concluded that patients may prefer to balance factors which are important to them and may choose to tolerate a level of pain if they perceive the analgesic side effects to be unacceptable.

Some of these issues will be discussed further in the Board of Science report on pain relief and analgesic use, which is due for publication in late summer/autumn 2016 and is intended to complement this project.

## 15. Views on a “good death”

Results from the 2012 British Social Attitudes survey (BSA) highlighted that the majority of people have some form of experience with death, with 96 per cent having attended a funeral of a family member, friend or work colleague at some point in their lives, and 63 per cent having experienced a death in the last five years.<sup>134</sup> Research suggests that many people’s views on a good death and end-of-life care are closely shaped by such experiences.<sup>135</sup>

There are common themes to people’s preferences for a good death and concerns and fears about dying. Among the factors which are generally seen to be important in end-of-life care are pain and symptom relief; not being a burden; being with family and friends; being listened to and receiving respect; privacy and dignity; and access to healthcare professionals and support.<sup>136,137</sup> A public poll conducted by Demos on behalf of the Sue Ryder organisation, which was published in 2013, found that being free from pain was important to most respondents (78%) followed by being surrounded by loved ones (71%), having privacy and dignity (53%) and being in familiar surroundings and in a calm and peaceful atmosphere (both 45%).<sup>138</sup> Being pain free was also ranked as most important out of six different factors relating to making a good death possible by most respondents (33%) in a 2015 ComRes survey commissioned by the National Council for Palliative Care. Having spiritual needs met was least important with 60 per cent of participants ranking that last. Fifteen per cent (15%) did not believe that a good death was possible (see Table 1 below).

**Table 1: Ranking of factors important to ensure a good death is possible – ComRes/NCPCC, 2015<sup>139</sup>**

Ranking:	Factors					
	Being pain free	Being with family and friends	Being cared for and able to die in the place of your choice	Retaining your dignity	Being involved in decisions about your care, or if you are not able to, for family or those close to you to be involved	Having spiritual needs met
1st	33%	17%	6%	13%	6%	5%
2nd	19%	18%	11%	19%	12%	2%
3rd	11%	17%	18%	16%	16%	3%
4th	9%	13%	20%	14%	20%	4%
5th	7%	12%	20%	14%	21%	6%
6th	3%	4%	5%	3%	5%	60%
I do not believe a good death is possible	15%					
Prefer not to say	5%					

The survey also asked respondents about their concerns about their death. The aspect of dying which most concerned people was lacking capacity to make their end-of-life wishes known (54%), followed by making adequate financial preparations (49%); end-of-life wishes not being met (43%); family disagreements over money or belongings (32%); and, lastly, funeral wishes not being followed (28%).

There is some evidence to suggest that fears of death and dying can vary depending on whether someone is from an ethnic minority group. A comparison of two population samples of older people from 2007-8 involving one sample which was more ethnically diverse and one which was more homogeneous, found that 77% of the more diverse group expressed up to four extreme fears of dying compared to 41% of the more homogenous sample.<sup>140</sup> Better quality of life was associated with reduced fears of dying in both samples. In the ethnically diverse sample, more extensive family support was related to higher anxiety about death amongst older people, as was having a longstanding illness.

## 16. Location

In theory, patients have the right to choose where to receive care and where they wish to die, whether that be a hospice, hospital, a care home, or their own home – although factors such as family support, resources, and medical condition are in practice, likely to influence the decision in some cases.<sup>141</sup>

There is evidence to suggest that people have strong views on where they would like to die. Numerous surveys and studies have shown that for the majority of people dying at home would be preferable to dying in hospital, in a hospice, a care home or similar setting: 67 per cent of the total respondents in the 2012 BSA survey expressed this view (although only 12 per cent had discussed their preferred place of death with someone).<sup>142</sup> Research suggests though that views on this issue can be complex, involving multifactorial preferences which can change over time and depending on different circumstances.

Preferences around place of care can differ between demographics, for example, in a study of older people's attitudes towards death, most respondents expressed a preference for hospice care rather than home care, but older respondents (aged over 75) expressed a preference for hospital care rather than home care.<sup>143</sup> Seymour *et al* found that the available research suggested men had fewer concerns about home death than women. Women also tended to report a preference for hospice over hospitals.<sup>144</sup>

Despite the general preference to die at home, only 21.6 per cent of individuals did so in England in 2010-12. In the same time period, over half of those who died in England died in hospital (50.4%). The others died in care homes (19.7%) and hospices (5.61%).<sup>145</sup> Similarly, in Wales in 2013, out of 32,000 deaths, 57 per cent took place in a hospital, 23 per cent at home, and 14 per cent in nursing or care homes. Data are not collected in Wales to measure whether the preferred place of death corresponds with the actual place of death. However, an increase in the percentage of people dying in their usual place of residence (either their own home or a care home), and a decrease in the percentage of people dying in hospital would suggest people's preferences are increasingly being met. Since 2008, the percentage of people dying at home in Wales has increased from 19.8 per cent to 22.6 per cent and in a care home from 12.3 per cent to 14.4 per cent. At the same time the percentage of people dying in hospital has fallen from 62.6 per cent to 56.7 per cent.<sup>146</sup>

Data from Scotland show that again, over half of individuals die in hospital.<sup>147</sup> The Scottish Government has established a national indicator to improve end-of-life care, which measures the percentage of the last six months of life which are spent at home or in a community setting. There has been little change in the achievement of this indicator between 2005/06 and 2013/14. The current percentage, 90.8 per cent compares with 90.4 per cent in the year 2005/06.<sup>148</sup>

In Northern Ireland in 2014, just under half (48%) of deaths took place in NHS hospitals. A further 29 per cent took place at home, followed by 23 per cent in other hospitals or nursing homes.<sup>149</sup> This is compared to 49 per cent of deaths which took place in hospital in 2011 and 51 per cent in 2009. This decrease in the number of hospital deaths has been attributed to the implementation of the *Living Matters, Dying Matters* strategy, as individuals and families increasingly indicate their preference to die at home.<sup>150</sup>

Local authority social services may provide a range of services and equipment to help patients remain at home. However, there are financial implications for this. Studies indicate that preferences around place of death can often be moderated by personal experience and concerns about being a burden.<sup>151</sup> Sixty per cent (60%) of respondents to the BSA survey changed their mind about dying at home if they would be without support, although one in three maintained they would have this preference irrespective of the support available.<sup>152</sup> Other concerns can affect a desire to die at home. A qualitative study which looked at the views of pancreatic cancer patients and their preferred place of death found that, although some of the people they interviewed wanted to die at home, this was only if they could do so with dignity and without burdening others.<sup>153</sup> There was also a concern expressed by participants that dying at home would result in the home then being associated with death for surviving family members. Other issues which have been shown to affect choices in this area are worries about dying at home intruding on private space<sup>154</sup> or fears of dying alone.<sup>155</sup>

The 2012 BSA survey analysed the preferences for place of death in the context of overall preferences for end-of-life care and found the two to be correlated rather than being considered in isolation.<sup>156</sup> People who preferred to die at home were most likely to prioritise being with friends and family, over pain relief and retaining dignity, whereas for respondents whose preferred place of death was a hospice being pain-free and retaining dignity were the most important factors followed by being peaceful and calm. The Demos research for Sue Ryder also suggested that people's preferences may change over the dying period with more people wanting to die in a hospice the closer they get to death and fewer people wanting to die at home, although the shift is most dramatic amongst those who have experience of hospice care.<sup>157</sup>

People also have fears and concerns in relation to caring at home for a loved one who is terminally ill. A 2015 public survey commissioned by Marie Curie investigated these concerns and found that 41 per cent of UK adults cited financial strains and 22 per cent cited worries about being able to take time off work as their biggest concerns about caring for a loved one who is ill.<sup>158</sup> Forty-four per cent (44%) also expressed concerns about not having access to 24/7 care and support. The study also highlighted concerns that the pain of a loved one might not be managed. There were some differences between the four nations in the UK. More respondents from Northern Ireland than any other country, for example, reported that pain management was their biggest concern (69%), whereas in Wales the biggest concern was the potential financial strain.

### 17. Discussions about death, end-of-life care and advance planning

The importance of open and honest discussion about death and dying is widely acknowledged as important for ensuring that individuals receive the care they would like at the end of life. Lack of discussion about end-of-life care can increase fear of dying and make decision making harder for relatives and health care professionals involved in the process. National policy on end-of-life care, such as the Department of Health's *End-of-life Care Strategy*, emphasises the importance of promoting awareness of discussion of end-of-life issues, and organisations like the National Council for Palliative Care (NCPC), which hosts the Dying Matters Coalition, have sought to normalise talking about death and dying and encourage people to make plans for the end of their life in the hope of changing attitudes and behaviours.<sup>159</sup>

There is evidence to suggest that, in general, individuals feel comfortable in discussing death. The 2012 BSA survey found that 70% of respondents expressed the view that they were comfortable with talking about death; however, only 31% had discussed with someone what exactly their wishes about their death would be.<sup>160</sup> Similar results were found in a 2015 survey conducted by ComRes on behalf of the NCPC, with 20 per cent stating that they had talked to someone about their end-of-life wishes and 18 per cent had asked a family member.<sup>161</sup>

Looking at preferences in more detail, the BSA survey found that, for example, only 8 per cent had discussed their wishes in relation to privacy and peace; 16 per cent had talked about dying with dignity; 8 per cent had discussed pain relief at the end of life; and 11 per cent had discussed their spiritual needs. The main reason provided for the lack of discussion was that death felt a long way off. Amongst those aged over 75, 23 per cent indicated this but 28 per cent said the main reason was that "other people do not want to talk to me about my death".<sup>162</sup>

The comfort individuals have in discussing death may not translate into their perceptions of others' comfort in discussing the issue. The 2015 ComRes/NCPC survey found that 72 per cent felt that people in Britain are uncomfortable talking about dying, death and bereavement, even though 64 per cent thought it was more acceptable to do so now than it was 10 years ago. Seventy-one per cent (71%) thought that if more people did so, it would be easier to have end-of-life wishes met.<sup>163</sup>

Although the results from the BSA survey suggest that individuals feel comfortable talking about dying, it also highlights that few people have made plans for the end of life. Only five per cent of people said they had a living will or advance care plan; only 11 per cent had written plans for their funeral; and just over three-quarters of respondents stated that they did not have any written plans in relation to their death.

### Part 6 – Access to end-of-life care and services

The end-of-life care strategies outlined at the beginning of this chapter make it clear that end-of-life care should be available in every area across the UK. However, as has been noted, the differing end-of-life care strategies and frameworks mean that this not always the case. In addition to these geographical vagaries in service provision, there are a number of other factors which can affect people's access to services.

## 18. Condition

Historically, end-of-life care has been more accessible for those suffering from cancer. Whilst improvements have been made in recent years, concerns continue to be expressed over the problems of access patients with some conditions continue to experience. In June 2015, Marie Curie published *Triggers for palliative care – improving access to care for people with diseases other than cancer*, which noted that over 71 per cent of deaths in England and Wales were caused by disease other than cancer, but yet only 12 per cent of palliative care in specialist in-patient units was provided for non-cancer diseases – including chronic obstructive pulmonary disease (COPD), dementia, end stage liver disease, motor neurone disease, multiple sclerosis, and Parkinson’s disease. The research found a number of barriers to accessing palliative care for non-cancer sufferers including:

- ‘Prognostic uncertainty and hard to predict disease trajectories;
- A failure or reluctance to identify certain conditions (e.g. dementia) as terminal by professionals;
- A lack of understanding of what palliative care is, and what it can achieve for people with conditions other than cancer, by both professionals and people with a terminal illness and their families;
- For some conditions, such as COPD, a paucity of research which demonstrates the potential benefits of palliative care on patients’ health outcomes (compared to the amount of research on lung cancer, for example);
- A lack of confidence from professionals in delivering care appropriate for people approaching the end of their life, for example, thinking that initiating end-of-life care discussions is someone else’s role or concerns about the legal standing of advance decisions; and
- Under-developed links between condition-specific specialists and palliative care specialists.’<sup>164</sup>

The report made a number of recommendations to government, to doctors and other health professionals, and researchers, which included calls for commitment to additional funding to ensure all those with a palliative care need can access services (regardless of their condition); demands for better education and training for all those involved in the care of people with a terminal illness; and better communication and stronger relationships between condition-specific specialists and palliative care specialists.

One qualitative study on the barriers to providing palliative care for older people in acute hospitals, for example, found that patients with non-malignant illness were less likely to get referred to specialist palliative care services, in part because of the historic link between cancer and palliative care.<sup>165</sup> Mitchell *et al* found that while the needs of non-cancer patients were acknowledged as being similar to those of cancer patients by the GPs in the study, the prolonged period of illness meant that identifying the palliative phase was more challenging and this impacted on their inclusion on the palliative care register.<sup>166</sup> Mason *et al* also found that people with advanced cancer were more likely to be identified as being appropriate for a palliative care approach and also that, on the whole, cancer patients received well-coordinated care and had a good understanding of their illness whereas other patients had a poor understanding.<sup>167</sup>

A recent summary report from the National Council for Palliative Care highlighted that between 2008 and 2014 there was a clear increase in patients with non-cancer diagnoses accessing specialist palliative care services, but also that the rate of change is slow, variability exists between services, and there continues to be a disparity of access.<sup>168</sup> In 2013-2014, the data show that the average proportion of people seen with non-cancer diagnoses in specialist palliative care services was 13.2 per cent for inpatients, 24 per cent for day care and 17.6 per cent for community care. Hospital support (26.4%) and outpatients (27.5%) had slightly higher averages.

In December 2012, the National Council for Palliative Care, in conjunction with various other organisations, published commissioning guidance to help ensure specialist palliative care is available to anyone who needs it, regardless of condition. This guidance sets out the factors that commissioners need to consider; sources of information and data; how value



and impact might begin to be measured; and some early evidence of the potential for cost reduction and cost avoidance. However, the report recognises that variance in services will continue to exist, as “commissioning an integrated service... must take into account local variations in service provision and funding streams”.<sup>169</sup>

A 2014 report on death and dying in Wales found considerable variation in the receipt of specialist palliative care between cancer and other terminal conditions. Under half (46.2%) of all cancer patients received specialist palliative care, compared to only 5.3 per cent of those with other, non-cancerous conditions.<sup>170</sup>

Evidence of similar discrepancies can be found in Scotland, where, according to a 2014 report by Marie Curie and Palliative Care Scotland, 80 per cent of non-cancer patients are not being identified in primary care for palliative care which would benefit them. This is compared to 75 per cent of those with a cancer diagnosis who were accessing palliative care.<sup>171</sup>

A variety of condition specific implementation frameworks and guidelines have been developed across the UK, including for heart failure,<sup>172</sup> liver failure,<sup>173</sup> motor neurone disease,<sup>174</sup> neurological conditions (including Alzheimer’s),<sup>175,176</sup> and older people living with frailty.<sup>177</sup> These provide advice on managing end-of-life care for patients with specific non-cancer conditions, but are dependent on the availability of services and are therefore guidelines only.

## 19. Black and minority ethnic groups

A 2013 report from Marie Curie highlighted that overall end-of-life and palliative care for black, Asian and minority ethnic (BAME) groups in the UK is often inadequate.<sup>178</sup> This represents both a current issue and also, given the projected increase in people from BAME backgrounds in all UK countries, a significant challenge going forward. (A similar report was published in 2015 by Marie Curie for palliative care in Scotland).<sup>179</sup> Calanzani *et al* included a literature review of the available systematic reviews, incorporating both qualitative and quantitative sources. The review drew on research both from the UK and internationally. The study authors found a range of issues associated with accessing care and low uptake of palliative care from the available evidence, including:

- lack of referrals to hospice or day care services;
- lack of knowledge amongst patients of what palliative care involves;
- low awareness of services;
- informational and language barriers;
- potential incompatibility of religious traditions or family roles with hospice care;
- location of services;
- previous negative experiences in accessing healthcare services generally;
- differences in age and medical conditions in BAME groups.<sup>180</sup>

In 2015 Dixon *et al* found, however, that the quantitative evidence suggests that people from BAME backgrounds are likely to have similar access to palliative care as people of white ethnicity.<sup>181</sup> The authors also conducted a new analysis of the data from the 2013 VOICES survey (discussed in more detail below) and in relation to access to palliative care and place of death, found that when compared to people of white ethnicity, people from BAME backgrounds were:

- no more or less likely to die in hospital than at home but were less likely to die in a care home than a hospital;
- more likely to receive support from community-based nurses and home help/meal on wheels;
- more likely to receive spiritual or emotional support;
- no more or less likely to receive support from Marie Curie nurses, social or support workers, hospice at home and rapid response services;
- less likely to feel as though they had support to care for their family member at home.<sup>182</sup>

Calanzani *et al* also identified a range of issues with respect to the care received by BAME patients from the available evidence. Communication was the most common issue, specifically with regard to a lack of sensitivity to cultural or religious needs (with lack of training in this respect highlighted) and the related issue of poor availability of translation

services leading to difficulties in assessing symptoms, diagnosing and prescribing.<sup>183</sup> The impact of this included the use of family members to translate, associated problems about confidentiality and information being censored, and stress amongst health professionals.<sup>184</sup> However, because much of the available evidence is from the US and has methodological limitations, Dixon *et al* caution that while it “may be useful in highlighting potential barriers and good practice in delivering palliative care to people from BAME groups, the generalisability of much of this evidence remains unclear”.<sup>185</sup> Their analysis from the VOICES data however did show that people from BAME backgrounds featured in the survey were less likely than those of white ethnicity to rate care as either “excellent” or “outstanding”. Moreover, BAME respondents were also less likely to rate the care received in care homes as “excellent”.<sup>186</sup>

## 20. Public perceptions of access to end-of-life care

There is some research on UK-wide awareness of palliative care and end of life services amongst the public. A ComRes poll of 2,601 UK adults, commissioned by Marie Curie in 2013, found that half of people said they would not know where to turn for practical support if someone close to them was terminally ill.<sup>187</sup> The results were relatively consistent at around 50 per cent across the four UK nations.<sup>188</sup>

As discussed above, experiences of death can be a strong influence on personal views about death and end-of-life care. The 2013 ComRes/Marie Curie poll found that personal experience of supporting someone at the end of life may exacerbate concerns people have about whether they will be able to receive the care they need. Only 8 per cent of respondents said that it made them less concerned compared to 45 per cent who were more concerned and 41 per cent who said it made no difference to their views. People who had supported someone who was at the end of life were more confident that medical and nursing support would be readily available to them (62%) compared to those with no recent experience of palliative care (57%), while both groups had the same level of confidence that the NHS would provide high quality care (47%).

The ComRes/NCPC survey in 2015 asked respondents how familiar they were with different terms associated with end-of-life care and dying and whether they had experience of it, knew what it was, had just heard of it, or had never heard of it. The results are given below in Table 2.

**Table 2: Familiarity with terms associated with death and dying – ComRes/NCPC, 2015<sup>189</sup>**

	Lasting power of attorney	Advance care planning	Hospice care	End-of-life care	Palliative care	A will
Know what it is and have direct experience of it	20%	6%	19%	16%	16%	47%
Heard of it and know what it is but have no direct experience of it	45%	33%	65%	53%	46%	45%
Heard of it but don't know what it is	19%	21%	8%	15%	17%	3%
Never heard of it	10%	32%	4%	10%	14%	2%
Prefer not to say	1%	1%	1%	1%	1%	1%
Don't know	5%	8%	4%	4%	6%	3%

A Scottish survey, although published in 2003, highlighted that the majority of the 3,000 respondents had some degree of knowledge about palliative care (49 per cent had some knowledge of palliative care, 16 per cent were found to have “quite a bit of knowledge” and just 3 per cent said they were very knowledgeable). A third reported having no knowledge. A majority of respondents also indicated that they would like more information to be generally available about palliative care services.<sup>190</sup>

Two recent research studies have looked at the awareness, accessibility and perceptions of palliative care in Northern Ireland, using both qualitative and quantitative methods. A cross-sectional questionnaire survey (600 respondents) sought views on two main issues: knowledge and attitudes regarding palliative care and the key barriers and strategies to bring about change.<sup>191</sup> Although 83 per cent had heard the term “palliative care”, 56 per cent had low knowledge of its meaning and 19 per cent had no knowledge. Palliative care was most closely associated with cancer or care of older people and its main aims were seen to be delivery of comfort (82%), pain relief (81.3%), and dignity (76.3%). Publicity campaigns were seen as key to raising awareness of palliative care and delivering key messages to the public. A qualitative study also looked at these issues in greater detail through 50 semi-structured telephone interviews and found similar results.<sup>192</sup> Participants’ knowledge of palliative care was mostly found to be influenced by personal or professional caring experiences or contact with care organisations. It was also recognised that myths, misunderstandings and anxieties remain in contemporary society around palliative care, death and dying. Media campaigns were again promoted as a solution to improving public awareness. For both studies, the authors caution that awareness levels could be lower than the findings given the response rate in the quantitative survey (17%) and because the study samples may not have been representative of wider society.

Research has also shown that awareness of, and access to, palliative care services can be influenced by other factors and can differ between population groups. As discussed in detail above, people dying from cancer, as opposed to those with non-malignant diseases, are more likely to have access to palliative care. There is also evidence to suggest that access to palliative care services amongst people with intellectual disabilities is low and engagement with services and care can be challenging for patients and healthcare professionals.<sup>193,194</sup> Other demographics may also affect awareness of services. (Factors relating to ethnic minority groups are discussed above). A study published in 2007 asked 252 cancer patients about their knowledge of palliative care, the role of hospices and the role of Macmillan nurses.<sup>195</sup> It found overall that 81.3 per cent of people either did not recognise the term palliative care or were mistaken about what it was, while 33.3 per cent did not understand the role of Macmillan nurses, and 32.2 per cent gave an incorrect description of the role of a hospice. As the study only included cancer patients it is possible that awareness may be lower for patients with other diseases. The authors found the recognition of “palliative care” and understanding of the role of Macmillan nurses to be higher among women. Another key finding was that social and material deprivation appeared to be the most significant factor affecting awareness of palliative care services, with those in the highest socio-economic group being eight times more likely to recognise the term “palliative care” and seven times more likely to understand the role of Macmillan nurses than those in the lowest grouping.

## Part 7 – Quality and experience of care

As the provision of healthcare is a devolved matter, there are no official UK-wide surveys which explore the quality of care provided to individuals at the end of life. The 2013 ComRes/Marie Curie poll, discussed above, touched on quality of care and support, with 68 per cent of people who knew someone who had died saying it was either very or fairly good, but 18 per cent saying it was poor.<sup>196</sup>

In 2014, the results of the *Let’s Talk About...* survey of patients and carers on palliative care reported its findings. The survey was led by the All-Ireland Institute of Hospice and Palliative Care and supported by the Department of Health, Social Services and Public Safety in Northern Ireland. Among the findings were the need for better and clearer communication, with 33 per cent saying they received too little information too late; 44 per cent of respondents saying family were involved and respected; 19 per cent saying family were put under too much pressure; and 18 per cent saying family were forgotten about or excluded.<sup>197</sup> When asked what they would most like to have been better in their experience, 39 per cent said coordination of care or treatment and 21 per cent said better emotional support. The Marie Curie survey, however, highlighted that people in Northern Ireland were particularly likely to say that the quality of care received was good.<sup>198</sup>

In Wales, patient views on care received from palliative and hospice care services are collected via a questionnaire. The system, which is run through iWantGreatCare (iWGC), uses simple survey forms which allow patients to provide qualitative and quantitative feedback. The forms collect views on nine aspects of care: trust, listening, whether the patient or carer would recommend the service, efficiency, cleanliness, respect, delays in care, how well staff addressed fears, and meeting needs. Aggregate data from the survey are not publicly available but, in 2011, the *Dying Well Matters* report stated that the average score across services was 9.6 out of 10.<sup>199</sup> Analysis of the free-text qualitative responses has also been published. This found that “patients and family members, usually also carers, recognised and prioritised good palliative care and highlighted the significance of the palliative care service in facilitating as well as providing care”.<sup>200</sup> There have been recent calls in a Marie Curie report to improve data collection in Wales in end-of-life care, because the iWGC survey has a number of limitations including low response rates. The introduction of a national bereavement survey, similar to that in England, was suggested in the report.<sup>201</sup>

#### **England – National Survey of Bereaved People (VOICES) 2011-2014**

In England, national data are collected annually through the *National Survey of Bereaved People (VOICES)*. There are no equivalent data collections which seek to capture patient or carer experience in Scotland or which are specific to Northern Ireland. The VOICES survey was initially commissioned by the Department of Health following a commitment in the *End-of-life Care Strategy* to carry out surveys of bereaved relatives. It is now commissioned by NHS England. Before the survey, very little information was systematically collected in England on quality of care at the end of life.

Data are collected by means of a questionnaire which is sent by post to the person who informed the registrar of the death, who is usually a relative or friend of the deceased. The questionnaire, sent to a sample of approximately 49,000 people each year, seeks the views of the bereaved on a range of issues including quality of care, dignity and respect, coordination of care, relief of pain and suffering, decision making, and preferences and choice at the end of life. The latest survey to report was in July 2015 for the 2014 questionnaire.<sup>202</sup> Details of some of the findings are given below, along with results from the previous years where relevant. In the 2014 survey, questions on overall levels of care in the last two days and non-medical needs were added for the first time to gauge how well needs were being met following the withdrawal of the Liverpool Care Pathway (LCP).

##### *– Quality of care*

In 2014, 12 per cent of VOICES respondents who gave views on the issue rated the quality of care in the last three months of life as outstanding. For 30 per cent the care was excellent, 33 per cent thought it was good, while 15 and 10 per cent thought the care was fair and poor respectively. There was no significant change in the ratings of care as either excellent or outstanding from 2011-14. There was not a significant difference for the perception of quality of care between different causes of death when the good, excellent and outstanding ratings are combined, but for excellent and outstanding only, quality of care for cancer patients is significantly higher (49%) than patients who died from cardiovascular disease (39%) or other causes (40%).

##### *– Dignity and respect*

The survey elicits views on how often staff treated the patient with dignity and respect, whether this was always, most of the time, some of the time, or never. Consistently across the surveys to date, hospice staff receive the largest proportion of “always” showing the patient dignity and respect in the last three months of life while hospital staff receive the lowest. Figures for all professionals in 2014 are given below in Table 3.

**Table 3: Dignity and respect showed to patients at the end of life – VOICES survey 2014<sup>203</sup>**

	Always	Most of the time	Some of the time	Never
Service provider	Weighted Percentage	Weighted Percentage	Weighted Percentage	Weighted Percentage
Community Nurses	76.6	15.6	5.4	2.5
GPs	69.0	17.5	9.7	3.9
Care Home	60.9	27.9	10.1	1.2
Hospital Doctors	59.0	25.4	13.3	2.2
Hospital Nurses	52.8	26.6	18.3	2.3
Hospice Doctors	88.2	7.4	3.3	1.1
Hospice Nurses	84.6	9.9	4.3	1.2

– *Coordination of care*

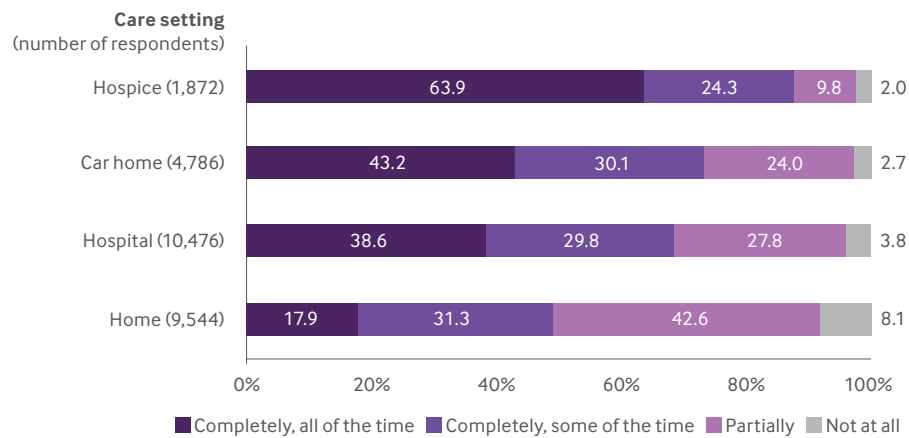
Views on how well community services worked together were sought in relation to patients who had spent some or all of the last three months at home. Of those who responded, 42 per cent said that services definitely worked well together and 15 per cent reported that they did not. In relation to patients who spent some time in hospital in the last three months of life, 30 per cent of respondents reported that the hospital, GP and other community services definitely worked well together, 36 per cent that they worked well to some extent and 33 per cent that they did not.

– *Relief of pain and suffering*

As discussed above, pain relief is often cited as the main consideration in people's views and fears in relation to their end-of-life care. Survey questions on the relief of pain were only relevant for certain patients. Analysis by care setting in 2014 showed that, where relevant, pain relief was reported as being provided "completely, all of the time" most frequently for patients in hospices (64%) and least frequently for those at home (18%). Two per cent (2%) reported that pain was "not at all" relieved in hospices; significantly more people reported that pain was not relieved at all at home (8%) than for other settings. Figure 3, below, details in full the results on how well pain was relieved during the last three months of life.

Whilst pain relief does not vary significantly between cause of death or age of death at home, in a hospital, or in a hospice, there is significant variation between cause of death in care homes: 22 per cent of cancer patients in care homes had their pain relieved all of the time, compared to just 13 per cent of patients with cardiovascular disease and 15 per cent of patients who died of other causes.<sup>204</sup>

**Pain was reported as being relieved “completely, all of the time” most frequently for patients in hospices (64%) and least frequently for those at home (18%)**



**Almost 1 in 13 (8%) of people cared for at home did not have their pain relieved at all.**

Percentages may not sum to 100 due to rounding

Figure 3 – Taken from Office for National Statistics (2015) *National Survey of Bereaved People (VOICES)*, 2014. ONS: London, p. 12.

#### – Decision making

Approximately three out of five (61%) respondents to the 2014 survey reported that no decisions had been made about care which the patient would not have wanted, although 19 per cent reported that unwanted decisions were made. The majority of patients (86%) were involved in decisions about their care as much as they wanted.

#### – Preferences for place of death

The VOICES survey in 2014 asked whether the patient had expressed a preference for where they wanted to die. In line with the research outlined above and consistent across the four surveys conducted since 2011, the majority of patients who had expressed a preference wanted to die at home (82% in 2014), compared with a hospice (8%), care home (6%), hospital (3%) or somewhere else (1%). Those surveyed were also asked whether the patient had died in the right place for their circumstances. Ninety-four per cent (94%) of respondents thought this was the case for those who died at home or in a hospice. For hospitals, fewer people (73%) thought that the patient had died in the right place, 16 per cent felt that hospital was not the right place, and 11 per cent were unsure. Previous VOICES surveys have also looked at preferences for place of death and found only half of patients who expressed a preference for dying at home actually died there.

#### – Overall care, non-medical needs and communication with relatives in the last two days of life

The 2014 survey found that three out of four respondents agreed that the patient’s need for pain relief (81%), fluids (79%) and nutrition (75%) were met in the last two days of life. With respect to non-medical needs, 70 per cent of respondents agreed that staff tried to ensure they were in the place they wanted to be and that emotional needs were supported, falling to 60 per cent for spiritual needs. Regarding communication and support, more than 86 per cent of bereaved people understood the information given to them by healthcare professionals but one in six disagreed that they had time to ask questions.

Another way to assess good practice is to look at standards of care provided at individual venues across the country. In England, the CQC now assesses each venue for end-of-life care services as part of its standard inspection. It looks at five main themes when reviewing each service: whether it is safe, effective, caring, responsive, and well-led. The CQC has released figures on quality of end-of-life care showing that in the first 62 trusts assessed, three were

rated as outstanding, 32 as good, 25 as requiring improvement, and one as inadequate. Frimley Park Hospital has been suggested as an example of good practice, receiving outstanding for its end of life care.<sup>205</sup> The main reasons for this appear to be the open approach to end-of-life care taken by staff (e.g. no stigma in discussing end of life and dying with colleagues or patients); high level management taking an active role in end-of-life care and thus disseminating it well across all services; good access to the expertise of the specialist palliative care team; and a robust discharge policy (with a one-day target for making the necessary arrangements for safe discharge). The hospital uses the AMBER care bundle system developed at Guy's and St Thomas' NHS Foundation Trust, which provides a systematic approach to managing the care of hospital patients who face uncertain recovery and are at risk of dying in the next one to two months. It encourages all those involved to continue with treatment in the hope of a recovery, while talking openly about patients' wishes and putting plans in place in the event of their death.<sup>206</sup> It consists of four elements:

- 'talking to the person and their family to let them know that the healthcare team has concerns about their condition, and to establish their preferences and wishes;
- deciding together how the person will be cared for should their condition get worse;
- documenting a medical plan; and
- agreeing these plans with all of the clinical team looking after the person'.

The patient's condition is then monitored closely and followed up on a daily basis to record any changes and address any concerns that they or their family may have.

In response to the fact that almost half of hospitals inspected since November 2013 have been criticised over patient safety concerns (particularly with regard to patients at the end of life), the CQC has launched a themed review of end-of-life care to understand why different people receive different experiences.<sup>207</sup> This review will focus on particular groups of patients, as well as looking at existing evidence on geographical variations and different care settings. At the time of writing, the findings were due to be published in late 2015.

## **Part 8 – Medical education and training**

### **21. Medical students and foundation year doctors**

The 2013 independent review into the Liverpool Care Pathway highlighted that medical training in palliative care was often inadequate and inconsistent.<sup>208</sup> In particular junior doctors reported that, although they may have had some form of exposure to palliative care at medical school, they felt their training had left them unprepared to care for dying patients.

There have been some qualitative studies which have looked at the views of medical students and junior doctors on the education and training they received whilst at medical school and their subsequent experiences of caring for dying patients and exposure to palliative care in their first years of medical practice. In a study published in 2011, Gibbins *et al* conducted 21 face-to-face interviews with newly qualified doctors in a UK deanery to establish what and how they learned about end-of-life care as students and in the first year as junior doctors.<sup>209</sup> The authors found that a lack of exposure to patients with palliative care needs and patients who were dying was common to all medical schools, and thus Foundation Year 1 (FY1) trainees felt unsure they had the skills or knowledge to provide end-of-life care. Patients who were dying were often not sought out by newly qualified doctors because training concentrated on clerking patients, and some respondents reported being kept away from dying patients by both senior medical and nursing care staff. Some interviewees also highlighted that because there was a lack of formal examination in palliative care, they did not perceive it to be important and so did not engage with the issue.

The level of education respondents perceived to have received also varied amongst participants with some reporting that they had received no training programmes whilst others felt they had extensive training. Many respondents felt that although they understood the general principles, they were unsure of how to apply these in practice, which the authors suggested was linked to the lack of direct clinical exposure. Less than a quarter of those who took part in the study realised they would be required to care directly for palliative care

patients. Once qualified, all respondents felt that they had been “thrown in at the deep end” and learned mostly through experience, with nurses helping newly qualified doctors, and guidance sought from specialist palliative care teams. They also reported that death was seen as “taboo” within hospital culture, with dying seen as a “failure”.

A similar study, from 2013 and based in the south east Scotland deanery, used both a questionnaire (60 respondents) and interviews with five FY1 doctors to find out if foundation year doctors felt able to care for patients and families with supportive and palliative care needs.<sup>210</sup> A further questionnaire was sent to 47 consultants to enable comparison of the two viewpoints. Forty eight per cent (48%) of the FY1 respondents felt that they did not have enough palliative care education at medical school and 67 per cent stated that they were not very well prepared to manage end of life issues in general. They felt they were most prepared for clinical communication and pain control and least well prepared for spiritual distress, social issues and psychological distress. The consultants surveyed did not expect FY1 doctors to be fully prepared following medical school but agreed that pain control was the area most prepared for, with spiritual distress and social care the least. Fifty-six of the 60 FY1 doctors had been involved in some way with caring for dying patients since qualification. Four out of five (79%) felt out of their depth but 91 per cent of these believed they had someone they could approach if they needed help. The study also looked at future training and asked both the FY1 and consultant participants what suggestions they had for improving it. Respondents from both groups suggested more practical or hands-on training with greater exposure to dying patients. A smaller proportion of FY1s also suggested more core teaching while consultants proposed undergraduate attachments to palliative care teams or ward-based teaching.

UK medical schools submit a Medical School Annual Return (MSAR) to the General Medical Council (GMC) each year, which is used to assess undergraduate medical education and training. In 2014, the GMC included a question requesting information about how medical schools have reflected on the *One Chance to Get it Right* report and whether they had made any changes to their curriculum. The responses show that there is variation of end-of-life care teaching across the country.<sup>211</sup> The GMC is now working with Health Education England (HEE) to look at end-of-life care teaching methods, assessment tools, and learning experience, in order to identify areas of “notable practice”.



## 22. Ongoing training needs

The training needs of the palliative care workforce have also been explored in other studies and in different settings. A qualitative study published in 2011, for example, explored the perceptions of out-of-hours palliative care amongst nine GPs and suggested that some doctors might not be comfortable with their level of training or knowledge in palliative care and needed regular educational support.<sup>212</sup>

Other research published in 2013, as part of a larger study looking at palliative care need in two acute hospitals, combined qualitative and quantitative methods to look at the perceptions of healthcare professionals regarding their education and training needs.<sup>213</sup> This study involved 58 healthcare professionals, involved in palliative care provision in primary or secondary care, whose views were sought through focus groups and individual interviews. Many participants, but particularly doctors and nurses working in non-specialist settings, felt they did not have adequate training or confidence in administering analgesics or in the communication skills required to engage in the sensitive discussions regarding prognosis or goals of palliative care. Some acknowledged, however, that education and training alone were not sufficient to instil a willingness to deliver a “person-centred approach”, and it was important to change beliefs and attitudes. The study also involved a questionnaire survey, which included 80 medical staff across all wards: 63 per cent of doctors felt they required more specific training in palliative care and 88 per cent stated that they would take up an offer of training. Regarding their previous training, 69 per cent had received specific palliative training in the last five years and a significant proportion had received it as part of their undergraduate degree.

## Chapter 2

# Practical challenges in end-of-life care

## Chapter 2

### Practical challenges in end-of-life care

Caring for patients at the end of life is never easy, whatever the training and experience of those providing it, but there are some aspects of providing such care that raise particular challenges. These are not only medical challenges. All doctors now need to work within an increasingly complex legal framework with which they are expected to be familiar. Additionally, the care doctors provide and their confidence in providing it, is not immune from events in the external environment. Although now some time ago, the aftermath of serial killer Harold Shipman's crimes, and the cynical abuse of his medical skills, still loom large in the public and profession's memory; what, if any, impact has this had on doctors' confidence to prescribe necessarily large doses of drugs to relieve pain at the end of life? The events with doctors explored their perceptions about some of these issues, specifically their views and confidence in relation to assessing mental capacity, diagnosing and treating depression at the end of life, prescribing pain relief in the post-Shipman era, and accurately predicting how long patients have to live. The parts that follow in this chapter, provide background information on each of these issues in turn; information about BMA members' views on the issues can be found in the second volume of this report, prepared by TNS BMRB.

#### Part One – Mental capacity and decision making at the end of life

Decision-making capacity refers to the everyday ability that individuals possess to make decisions to take actions that influence their life. In a legal context it refers to a person's ability to do something that may have legal consequences such as entering into a contract, or consenting to medical treatment. In the UK, the law on assessing mental capacity is set out in the Mental Capacity Act 2005 in England and Wales, the Adults with Incapacity (Scotland) Act 2000 in Scotland and the common law in Northern Ireland. This part of the chapter explains the legal basis for assessments of capacity to give, or withhold, consent for medical treatment, including life-prolonging treatment.

#### 1. Mental capacity and treatment

Adults with capacity have the right to consent to, or refuse, medical treatment irrespective of the consequences (except where compulsory treatment is authorised under mental health legislation). Throughout the UK, capacity is presumed in those aged 16 or over and an assessment of capacity is only required where there are grounds to suggest that capacity may be lacking. In practice, unless they are unconscious, patients usually retain some degree of capacity and are able to make some decisions. The test of capacity is functional; doctors' assessments are therefore focussed on the particular decision that needs to be made and whether the individual is able to make it at the time it is needed. Capacity can often fluctuate over time and, particularly in some groups of patients such as those with dementia, depending on the particular circumstances and time of day. When assessing an individual's capacity, doctors must always consider the nature and implications of the decision that needs to be made as well as the patient's ability to make the decision – this means considering both the seriousness of the decision and also its complexity. Many decisions with serious consequences will be complex but others may be relatively straightforward. Decisions about capacity to consent to or refuse medical treatment are usually made by the treating doctor although more specialist advice may be sought where capacity is in doubt or, for example, there is a psychiatric or psychological disorder that might impair judgement. Ultimately capacity is a legal concept and if there is doubt about a patient's capacity, the courts can be asked to decide, taking into account evidence from doctors as appropriate. The law relating to mental capacity differs around the UK.

## 2. Mental Capacity Act 2005

The Mental Capacity Act came into force in England and Wales in 2007 and provides a framework for decision making for people aged 16 or over who lack the capacity to make a specific decision for themselves. The Act is supported by a statutory code of practice which provides detailed guidance on how the Act should be used.<sup>214</sup> Under the Act, a person lacks capacity if, at the time the decision needs to be made, he or she is unable either to make or to communicate a decision as a result of “an impairment of, or disturbance in the functioning of, the mind or brain”. The Act sets out a number of basic principles that must govern decisions made and actions taken on behalf of adults who lack capacity which include the following.

– *A person must be assumed to have capacity unless it is established that he or she lacks capacity.*

All people over the age of 16 are presumed to have capacity unless there is evidence to the contrary. Where there are doubts about the individual’s capacity to make a particular decision, the reasons for this should be recorded in the medical record along with details of the assessment process undertaken and the outcome. Decisions must not be based on irrelevant factors such as a patient’s age, appearance or disability or on unfounded assumptions about their condition or behaviour. Many patients with a diagnosis of dementia, for example, nonetheless have the capacity to make decisions for themselves, particularly in the early stages, and it is important that assumptions are not made based on the patient’s diagnosis. The focus has to be on the individual’s ability to make the decision in question at the time the decision needs to be made.

– *A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.*

Before a decision is made that an individual lacks capacity, everything practicable must be done to support the patient to make his or her own decision. This may involve using a variety of practical methods such as the use of advocates, pictures,<sup>215</sup> language and communication support, and assessing capacity at the time most favourable for the individual. Where capacity fluctuates and the decision can wait, it should be delayed until the patient is best able to contribute. Some groups of patients, such as those with dementia or learning disabilities, will need extra support to maximise their ability to participate in decisions about their care.

– *A person is not to be treated as unable to make a decision merely because he makes an unwise decision.*

It is a long-established legal principle that adults with capacity have the right to refuse medical treatment or diagnostic procedures for reasons that are ‘rational, irrational or for no reason’.<sup>216</sup> The fact that an individual makes a rash, unwise or irrational decision is not itself proof of incapacity. Where such actions are out of character, or follow an accident or a period of illness, questions may arise about capacity, but they are not in themselves determinative of a lack of capacity. Such factors would indicate that further investigation is required and possibly a referral made for more specialist assessment.

– *An act done, or decision made, must be in the individual’s best interests.*

“Best interests” is broader than best medical interests and must take account of all relevant factors. The Act provides a checklist of what factors must be taken into account when making best interests judgements including the past or present wishes, feelings and beliefs of the individual as far as they can be ascertained and the views of those close to the patient, and relevant others, about the individual’s wishes, feelings, beliefs or values that might have an impact on the decision.

### Assessing capacity

Where there are grounds to doubt that the patient has the capacity to make the decision required, the Act uses a two stage assessment of capacity:

- Is there an impairment of, or disturbance in the functioning of, the mind or brain? If so:
- Is the impairment or disturbance sufficient that the person is unable to make that particular decision?

In some cases, with due regard to confidentiality, it may be appropriate also to take into account the views of those close to the individual as part of the assessment of capacity. Family members and close friends may be able to provide valuable background information, although their views about what they might want for the individual must not be allowed to influence the assessment.

An individual is regarded as unable to make a decision if, at the time the decision needs to be made, he or she is unable:

- to understand the information relevant to the decision;
- to retain the information relevant to the decision;
- to use or weigh the information;
- to communicate the decision (by any means).<sup>217</sup>

Where an individual fails one or more parts of this test, then the entire test is failed and the individual does not have the capacity to make the relevant decision. If they have appointed an attorney or attorneys in a registered Lasting Power of Attorney (Health and Welfare), then the attorney is empowered to make most decisions for them. Where it is determined that a patient lacks the capacity required to make a decision, there is no appointed attorney, and the individual has not made a valid advance decision refusing the treatment, the decision must be made in his or her best interests. This requires a best interest meeting, with those who know the patient well being invited. More information about the Mental Capacity Act and its practical application, including an interactive tool to assist with the assessment of capacity, can be found on the BMA website at: <http://bma.org.uk/practical-support-at-work/ethics/mental-capacity>

### Deprivation of Liberty Safeguards (DoLS)

The Mental Capacity Act contains specific provisions for individuals who lack capacity and are “deprived of their liberty”, whereby legal authorisation, in a particular form, is required. A 2014 judgment from the Supreme Court, concerning the criteria for judging whether an individual has been deprived of his or her liberty, has significantly expanded the group of patients that fall into this category.<sup>218</sup> The purpose of their deprivation is irrelevant and so where patients are “de facto detained” in the course of providing medical care and treatment, which is in their best interests, the requirements of the Act are nonetheless invoked. Factors that indicate that an individual may be deprived of liberty include:

- that the person is confined to a restricted place for a non-negligible period of time;
- that the person does not have the capacity to consent to the restrictions;
- that the person is subject to “continuous and complete supervision and control”; and
- that the person is not free to leave.

These factors will be met in the case of a few patients who are coming to the end of their lives and are being cared for in a hospital or hospice setting. Department of Health guidance relating to palliative care provision specifies that if the person has capacity to consent to the arrangements for their care at the time of their admission or at a time before losing capacity, and does consent, the Department considers this consent to cover the period until death and that hence there is no deprivation of liberty.<sup>219</sup>

The DoLS system is currently under review but until any changes are made to the law, doctors need to be aware of the requirements this places on them, which includes reporting to a coroner any death where a DoLS is in place. The BMA has produced guidance to help those doctors who need to work within this system<sup>220</sup> which can be found on the BMA website.

### Use and understanding of the Mental Capacity Act

Although the Mental Capacity Act has been in force for a number of years, knowledge of and compliance with its terms are variable. In 2014 the House of Lords published a post-legislative scrutiny report on the Mental Capacity Act, assessing how well it was working in practice.<sup>221</sup> The report was very critical. Amongst its findings were that there was a general lack of awareness of the Act and its requirements; the necessary shift of attitude from “protection and paternalism” to “enablement and empowerment” had not occurred; and the presumption of capacity was poorly understood and this sometimes led to a failure to conduct a formal assessment of capacity in cases where such an assessment would have been appropriate. The quality of assessments was also criticised by a number of those giving evidence to the Lords committee. Serious criticism was also levelled at the complexity and bureaucratic nature of the deprivation of liberty safeguards, which it concluded were “not fit for purpose” and needed replacing.

### 3. Adults with Incapacity (Scotland) Act 2000

The Adults with Incapacity (Scotland) Act 2000 provides a framework for decision making for people aged 16 or over who lack the capacity to make a specific decision for themselves in Scotland. The Act is supported by a statutory code of practice which provides detailed guidance on how the Act should be used.<sup>222</sup> The Act sets out a number of basic principles that must govern decisions made and actions taken on behalf of adults who lack capacity including the following.

- *The person proposing an intervention must be satisfied that it will benefit the individual and that the desired benefit cannot reasonably be achieved without the intervention.*

Benefit in this context has its ordinary meaning of an advantage or net gain for the patient. It is broader than clinical benefit and includes other less tangible advantages such as respecting the patient’s known wishes and values.

- *Enhance the patient’s capacity and encourage him or her to exercise any residual capacity.* Some patients’ capacity can fluctuate with their condition, medication, mood or the time of day. Every effort should be made to maximise the individual’s ability to participate in decision making to the greatest extent possible. There is a statutory duty on those acting under the Act to encourage patients to use their existing skills and develop new ones.

- *Take account of the past and present wishes and feelings of the individual where these can be ascertained through any means and consult with relevant others where it is reasonable and practicable to do so.*

Any decisions affecting an adult with incapacity must take account of that individual’s past and present wishes through any means available to do so and the views of those who have legal authority to make decisions on behalf of the individual. With due regard to confidentiality, there should also be consultation with relevant others.

#### Assessing capacity

Under the Act, an adult lacks capacity if he or she is incapable of:

- acting;
- making decisions;
- communicating decisions;
- understanding decisions; or
- retaining the memory of decisions.

in relation to any particular matter, by reason of mental disorder or of inability to communicate because of physical disability or neurological impairment.

The code of practice emphasises that adults should not be seen as lacking capacity solely because they are suffering from a specific condition or disorder, including the following:

- having a psychotic illness;
- having dementia, particularly in the early stages;
- having communication difficulties;
- having a brain injury or other physical disability;
- disagreeing with the advice or treatment offered by health professionals.<sup>223</sup>

The code of practice also states that, in relation to medical treatment, an assessment of mental capacity will ordinarily try to establish whether the individual:

- is capable of making and communicating the decision;
- understands the nature of what is being asked and why;
- has memory abilities that allow the retention of information;
- is aware of any alternatives;
- has knowledge of the risks and benefits involved;
- is aware that such information is of personal relevance to them;
- is aware of their right to, and how to, refuse, as well as the consequences of refusal;
- has ever expressed their wishes relevant to the issue when greater capacity existed;
- is expressing views consistent with their previously preferred moral, cultural, family, and experiential background;
- is not under undue influence from a relative, carer or other third party declaring an interest in the care and treatment of the adult.

When assessing capacity, carers and relatives can have valuable information about the patient and about his or her past and present wishes and feelings. Account should also be taken of anyone else with an interest in the welfare of the adult or the intervention. This does not, however, require health professionals to go to undue lengths to seek out such people. In addition, care needs to be taken to respect confidentiality and to ensure that the relatives' views about what they might want for the patient do not influence the assessment of capacity.

Where it is determined that an individual lacks the capacity to consent, except in emergency situations, a certificate of incapacity must be sought and treatment that will "benefit" the patient may be provided under the general authority to treat. More information about the Adults with Incapacity (Scotland) Act can be found on the BMA website at: <http://bma.org.uk/practical-support-at-work/ethics/mental-capacity>

#### 4. The common law in Northern Ireland

There is currently no specific legislation on mental capacity in Northern Ireland although a draft mental capacity bill is currently undergoing legislative scrutiny which will enshrine, in statute, the assumption of capacity. At the present time, mental capacity and treatment decisions for those who lack capacity are governed by the common law. The basic principles in the English and Scottish legislation were based on the common law and so the situation in Northern Ireland is very similar to that in other parts of the UK. The presumption of capacity for those aged 16 and over, and the functional nature of capacity assessments, for example, are the same throughout the UK.

The common law sets out a three-stage test of capacity which was developed in the case of *Re C*.<sup>224</sup> An individual has the capacity to make a decision if, at the time the decision needs to be made, he or she can:

- comprehend and retain the relevant information;
- believe the information; and
- weigh the information, balancing risks and benefits, in order to arrive at a choice.

This three-stage test has been elaborated over time and it is now widely accepted that when doctors are involved in assessing a patient's ability to make specified decisions, they will need to identify whether he or she is able to:

- understand in simple language what the medical treatment is, its purpose and nature and why it is being proposed;
- understand its principal risks, benefits and alternatives;
- understand in broad terms what will be the consequences of not receiving the proposed treatment;
- retain the information for long enough to make an effective decision;
- weigh the information in the balance; and
- make a free choice (i.e. free from any pressure or coercion).

The ethical obligations to enhance the individual's capacity and ability to participate in decision making to the greatest extent possible, and to take account of the individual's past and present wishes and values in making treatment decisions, also apply in Northern Ireland.

## 5. Mental capacity and treatment decisions at the end of life

The principles set out above apply equally to treatment decisions at the end of life as at other times, including decisions to refuse life-prolonging treatment. With any patient, capacity to make and communicate decisions can fluctuate and be affected by pain, illness, confusion, dementia, cognitive impairment, serious mental illness – such as, but not limited to depression - or the effects of medication but this can be a particular concern as patients near the end of their lives. Capacity and the ability to participate can be enhanced with treatment or symptom-management. Management of pain, for example, can mean a patient is more able to take part in decision making. Similarly, the effects of medication can affect capacity. Whenever possible, patients should be given the opportunity to express their views when any detrimental effects of medication are absent or at a minimum. The effects of some medications take a long time to diminish, and doctors need to judge whether it would be appropriate to allow time for these long-term effects to dissipate before assessing capacity. Doctors must keep in mind that patients may change their minds, and that a capacity assessment is only valid for a particular decision at a particular point in time.

Depression and anxiety can be difficult to recognise, but may also interfere with capacity. Someone with depression may be able to understand and retain the information relevant to the decision, but feel so hopeless that any treatment seems pointless, even though there is a good chance of recovery. This could mean that they are unable to use or weigh the information, and so may be deemed to lack capacity.<sup>225</sup> The identification and treatment of depression and anxiety is, therefore, an important consideration in assessing capacity and in terms of care-planning at the end of life.

### Key principles in providing end of life care

- It is not an appropriate goal of medicine to prolong life at all costs.
- Where treatment is unable to provide a net benefit to the patient, serious consideration should be given to whether it is appropriate to provide it.
- Where a patient lacks capacity, any treatment provided must be in his or her best interests/benefit, taking account of the benefits and burdens of the treatment and the individual's wishes and beliefs.
- Any decision made on behalf of a patient who lacks capacity must not be made with the intention of ending the patient's life.
- Patients with capacity have the right to refuse treatment even if that refusal will result in an earlier death.
- A valid and applicable advance decision to refuse treatment is likely to be legally binding.
- It is not unlawful to prescribe strong pain relief or sedatives, even if that might risk hastening death, provided the intention is to relieve the patient's suffering and the dosage is proportionate to that intention.
- Suicide is not against the law but it is unlawful for someone to assist a person to commit suicide.

## Part Two – Depression at the end of life

There are a number of mental disorders which doctors should be aware of when treating patients at the end of life. These include anxiety and depression. Depression is a common mental disorder that can cause people to experience, for a short or prolonged period of time (usually two weeks or more), depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration.<sup>226</sup>

The term depression can be taken to refer to a variety of conditions, from a symptom of low mood or a range of less well-defined symptoms to the well-defined clinical syndrome of major depressive disorder.<sup>227</sup> Much of the work carried out on depression at the end of life has tended to focus on the clinically defined major depressive disorders. However, much



of what is discussed in this section will also be applicable to individuals with depressive symptoms, without meeting the criteria for a full disorder.

There are two main sets of diagnostic criteria used to diagnose depression. The most commonly used criteria in the UK and Europe are the World Health Organization's (WHO) *International Classification of Diseases*, 10th edition (ICD-10).

**“ICD-10 criteria of a depressive episode:**

In typical depressive episodes of all three varieties described below (mild, moderate and severe), the individual usually suffers from depressed mood, loss of interest and enjoyment, and reduced energy, leading to increased fatigability and diminished activity. Marked tiredness after only slight effort is common. Other common symptoms are:

- (a) reduced concentration and attention;
- (b) reduced self-esteem and self-confidence;
- (c) ideas of guilt and unworthiness (even in a mild type of episode);
- (d) bleak and pessimistic views of the future;
- (e) ideas or acts of self-harm or suicide;
- (f) disturbed sleep;
- (g) diminished appetite.

The lowered mood varies little from day to day and is often unresponsive to circumstances, yet may show a characteristic diurnal variation as the day goes on. As with manic episodes, the clinical presentation shows marked individual variations and atypical presentations are particularly common in adolescence... For depressive episodes of all three grades of severity, a duration of at least two weeks is usually required for diagnosis, but shorter periods may be reasonable if symptoms are unusually severe and of rapid onset.

**Mild depressive episode:** Depressed mood, loss of interest and enjoyment and increased fatigability are usually regarded as the most typical symptoms of depression, and at least two of these, plus at least two of the other symptoms [as outlined above] should usually be present for a definite diagnosis. Minimum duration of the whole episode is about two weeks. An individual is usually distressed by the symptoms and has some difficulty in continuing with ordinary work and social activities, but will probably not cease to function completely.

**Moderate depressive episode:** At least two of the three most typical symptoms noted for mild depressive episodes should be present, plus at least three (and preferably four) of the other symptoms. Several symptoms are likely to be present to a marked degree, but this is not essential if a particularly wide variety of symptoms is present overall. Minimum duration of the whole episode is about two weeks. An individual will usually have considerable difficulty in continuing with social, work, or domestic activities.

**Severe depressive episode:** All three of the typical symptoms noted for mild and moderate depressive episodes should be present, plus at least four other symptoms, some of which should be of severe intensity. The depressive episode should usually last at least two weeks, but if the symptoms are particularly severe and of very rapid onset, it may be justified to make this diagnosis after less than two weeks. During a severe depressive episode, it is very unlikely that the sufferer will be able to continue with social, work, or domestic activities, except to a very limited extent.”<sup>228</sup>

However, much of the work carried out on depression at the end of life, and discussed in this chapter, has used the criteria of the American Psychiatric Association's *Diagnostic and Statistical Manual*, 5th edition (DSM-V).

**“DSM-V criteria of a major depressive episode:**

- A. Five or more of the following symptoms have been present during the same 2-week period and represent change from previous functioning: at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure. Note: do not include symptoms that are clearly attributable to another medical condition.
- (1) Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, and hopeless) or observation made by others (e.g., appears tearful). (Note: In children and adolescents, can be irritable mood).
  - (2) Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).
  - (3) Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day. (Note: In children, consider failure to make expected weight gain).
  - (4) Insomnia or hypersomnia nearly every day.
  - (5) Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
  - (6) Fatigue or loss of energy nearly every day.
  - (7) Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
  - (8) Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
  - (9) Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.
- B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- C. The episode is not attributable to the physiological effects of a substance or to another medical condition.”<sup>229</sup>

Atypical presentations can be particularly common in adolescence, in people with intellectual disabilities, and in older people.

There are a number of different screening tools which can be used to identify depression in patients, which will be explored in more detail below. Similarly, there are a range of treatment options, the choice of which will be dependent on the individual and on the severity of the condition. However, it is most commonly treated in a number of ways, usually involving medication, talking therapies, self-help, or a combination of all three.

## 6. Depression amongst the elderly population

### Prevalence

Depression can be a common response to the ageing process. It is estimated that 1-4 per cent of the general elderly population (usually defined as over 65 years of age) has major depression.<sup>230</sup> The prevalence of major depression appears to double after the age of 70.<sup>231</sup> It has been reported that the prevalence of major depression in the over 75s ranges from 4.6 per cent to 9.3 per cent.<sup>232</sup> More minor depressive disorders may occur in up to 13 per cent of the elderly population,<sup>233</sup> and in up to 37.4 per cent of the over-75s.<sup>234</sup> Women are more likely than men to be affected, in keeping with patterns of depression found in other age groups. However, some have suggested that the incidence of depression may be overestimated in older people, due to the reliance of the National Institute for Health and Care Excellence's (NICE) guidance on scales of severity weighted towards the presence of somatic symptoms.<sup>235</sup>

Depressive conditions are more likely to be found in medical settings than in the community. Around 10–12 per cent of elderly patients admitted to hospital have major depression, compared to around 6–9 per cent in primary care settings.<sup>236</sup> Individuals living in care homes may also be particularly susceptible, with one large study of individuals in long-term care facilities indicating major depression in 12.4 per cent of patients and “significant depressive symptoms” in 35 per cent.<sup>237</sup>

### Screening and identification

There are a number of different depression-specific screening tools which are used across a range of settings.

#### Commonly used depression-specific screening tools

<b>Single item</b>	“Are you depressed?”
<b>Two item</b>	“During the last month, have you been bothered by feeling down, depressed, or hopeless?” “During the last month, have you been bothered by having little interest or pleasure in doing things?”
<b>Hospital Anxiety and Depression Scale (HADS)</b>	14 items, 7 for anxiety, 7 for depression. Excludes somatic symptoms such as fatigue or insomnia, and has the aim of creating a tool for the detection of anxiety and depression in people with physical health problems.
<b>Patient Health Questionnaire (PHQ-9)</b>	“Over the last two weeks, how often have you been bothered by any of the following problems?” 9 items covering little interest or pleasure in doing things; feeling down, depressed, or hopeless; trouble falling or staying asleep or sleeping too much; feeling tired or having little energy; poor appetite or overeating; feeling bad about oneself; trouble concentrating on things; moving or speaking so slowly that other people could have noticed – or the opposite, being fidgety or restless; thoughts of self-harm or “being better off dead”.  “If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?” Four possible responses: not difficult at all; somewhat difficult; very difficult; and extremely difficult.

There are, however, a number of problems with using the standardised diagnostic criteria for depression, and in using these traditional screening methods, when treating older adults. The diagnostic criteria detailed in ICD-10 and DSM-V are derived from younger adults, and when applied to an older population, may fail to take into account the impact that general ageing, and age-related conditions, might have on the presentation of depression. Both ICD-10 and DSM-V adopt an aetiological approach, so that symptoms that can be attributed to other physical conditions will not be diagnosed as depression.<sup>238</sup> In old age, depression is very often co-morbid with physical disorders such as diabetes and heart disease. It is particularly associated with neurological diseases such as Parkinson's disease (occurring in between 20 and 40 per cent of patients<sup>239</sup>) and dementia (occurring in around 30 per cent of patients with Alzheimer's disease, but with a possible range of up to 86 per cent).<sup>240</sup>

Various studies have shown that the elderly are significantly less likely than younger adults to recognise depressive symptoms.<sup>241</sup> They may believe that what they are feeling is a natural reaction to many of the losses associated with ageing – e.g. bereavement, loss of independence, or a change of role or fall in socio-economic status.<sup>242</sup> This may also be due in part to a reluctance amongst older generations to discuss depressed or low mood, and the stigma of mental illness that can persist in this group.

Whilst the diagnostic criteria remain the same for diagnosing depression in elderly and younger adults, some symptoms may be more prominent in later life depression. Cognitive impairment, psychomotor retardation, and anxiety are all more common in older adults, and this should be taken into account in the diagnosis process.<sup>243</sup>

A screening tool known as the Geriatric Depression Scale (GDS) was developed specifically for use in the elderly, in order to address some of the problems identified above. It involves a 15-item test which includes questions on satisfaction with life, interests and activities, and feelings of helplessness and hopelessness, and has become one of the most widely used instruments for the screening of depression in later life.<sup>244</sup>

### **Treatment**

In some milder forms of depression, psychosocial interventions may be sufficient to cause an improvement. This might include increasing social contact, adding more structure to the day, or introducing an exercise programme.<sup>245</sup> In some more severe forms of depression, psychological and drug treatment have been shown to be as effective in older adults as they are in younger adults.<sup>246</sup>

The long term prognosis for depression in the elderly is considered mixed, with patients over the age of 70 being particularly susceptible to relapse.<sup>247</sup> Effective treatment, however, can be achieved and maintained. One American study noted a highly significant effect for active treatment over placebo in preventing recurrence of major depressive episodes.<sup>248</sup> There was a 20 per cent recurrence rate for patients on combined anti-depressant and interpersonal therapy over three years, compared with a 90 per cent recurrence rate for patients on placebo. The authors noted that combined therapy of anti-depressants and psychotherapy is the "optimal clinical strategy" in preserving recovery in elderly patients with recurrent major depression.

## **7. Depression amongst those diagnosed with a terminal illness**

### **Prevalence**

A terminal diagnosis induces a range of reactions in individuals. Some might feel numb at first, while others may feel strangely calm or matter of fact, or even appear to be in denial. As time passes, they may experience a range of emotions, including shock, fear, anger, helplessness and frustration.<sup>249</sup>

In some situations, an individual's presentation might go beyond that of a "normal" reaction to the news of a terminal illness, and may be an indication of a psychiatric condition, like depression or other depressive disorders.

The available research on depression in terminal patients is largely based on small samples of patients with very high non-participation rates.<sup>250</sup> However, there is general agreement that depression is a common problem in palliative care settings, with some estimates suggesting that the prevalence of major depression may be up to twice as high as that found in the general population.<sup>251</sup>

The prevalence of depression in palliative care varies depending on type and stage of disease, care setting and population characteristics. Research findings vary hugely in reports about the incidence of major depression in terminally ill patients, with one paper suggesting a range from 3.7 per cent to 58 per cent.<sup>252</sup> Another estimates the incidence at being somewhere between 25 per cent and 77 per cent.<sup>253</sup> Research into the incidence of depression amongst patients with varying stages of cancer has been reported as showing that 47 per cent fulfilled diagnostic criteria for psychiatric disorders, with 68 per cent of them displaying depressed mood.<sup>254</sup> A review of all literature on depression in patients with advanced cancer and mixed hospice populations suggested that the best estimates place the prevalence of major depression at 15 per cent, with different methods of screening suggesting a prevalence of up to 29 per cent.<sup>255</sup>

The wide variation of prevalence is due, in part, to the different definitions of depression used, ranging from a specific diagnosis; a looser term indicating significant distress; and a colloquial term suggesting distress or unhappiness.<sup>256</sup> As will be explored in more detail below, the variation in rates of prevalence may also be due to the lack of consistency in screening tools.

As with much of the evidence available on palliative care, the majority of evidence on depression in palliative care settings comes from patients with cancer. However, one study of the prevalence of depression in palliative care populations actually found that the prevalence of depression was higher for patients with non-cancer diagnoses.<sup>257</sup> They concluded that their result was most likely due to a referral bias – non-cancer patients with high psychological distress are more likely to be referred to specialist palliative care. Additionally, the study found that the prevalence of depression varied by “performance status”, and that depression was most common in patients who were most restricted in their daily activities – which may tend to be patients with especially disabling non-cancer conditions (e.g. advanced degenerative neurological conditions).

### Screening and identification

The true prevalence of depression is quite possibly unknown due to a frequent lack of identification by clinicians, and is subsequently often undertreated in palliative care settings. The evidence that does exist is heavily weighted towards cancer patients, meaning that far less is known about depression in patients with end-stage pulmonary, cardiac, renal, or neurological disease.<sup>258</sup> Some have indicated that up to 80 per cent of the psychological and psychiatric morbidity which develops in cancer patients goes unrecognised and untreated.<sup>259</sup> A UK screening programme designed to identify cases of Major Depressive Disorder (MDD) in outpatient cancer centres in 2004, found that of the cases of MDD identified, only 15 per cent had been receiving evidence-based treatment. Only half had discussed their low mood with their GP or oncologist, and less than a third reported being offered any anti-depressant medication. Only 7 per cent had been referred to specialist mental health services, and only 5 per cent had received any formal psychological treatment.<sup>260</sup> In general practice, referrals and anti-depressant prescriptions are significantly less likely for older patients and patients with diabetes, heart disease, and other chronic conditions.<sup>261</sup>

There are a number of reasons why depression is under-recognised in patients at the end of life:

- Both patients and clinicians can believe that psychological distress is an inevitable part of the dying process, and physicians may experience difficulty in differentiating between clinical depression and “appropriate sadness”;<sup>262</sup>
- Physicians treating terminally ill patients may lack the clinical knowledge and skills to identify many psychiatric problems;<sup>263</sup>
- There is a shortage of psychiatrists specialising in the treatment of mental illness at the end of life;

- Many depressive symptoms such as fatigue, loss of appetite, and weight loss can be attributed to many of the physical symptoms of terminal illness and its treatment;<sup>264</sup>
- Patients and clinicians may wish to avoid exploration of psychological issues due to concerns that such exploration will cause further distress;<sup>265,266</sup>
- Physicians caring for dying patients may feel a sense of hopelessness which can lead to a therapeutic nihilism.<sup>267</sup>

Various authors have also noted the importance of recognising that meanings and expression of depressive symptoms may vary across cultures.<sup>268</sup> Religious and cultural beliefs about death and dying can influence a patient's response to the crisis of terminal illness.<sup>269</sup>

The detection of depression in palliative care settings has been described as “bedevilled by a plethora of tools and a paucity of evidence”.<sup>270</sup> One study which carried out a literature review of depression assessment and classification in palliative care cancer patients found huge variation in the usage of assessment methods – up to 106 different methods for assessing depression and distress were used by clinicians.<sup>271</sup> The authors concluded that there was a clear need for consistency in conceptualising depression and associated conditions in palliative care settings, and urged future work on the development of guidelines for assessment and classification. A separate study asked a multi-professional expert group to complete a structured questionnaire on the best choice of screening tool for depression in palliative care.<sup>272</sup> The questionnaire returned a broad range of results, indicating discordance in the views of experts. Generally speaking, “routine informal asking” was rated more highly by all participants than formal screening tools such as the Hospital Anxiety and Depression Scale (HADS) outlined above. This was largely attributed to the fact that both clinicians and patients may feel more relaxed and open if mood is considered as part of a more general conversation about patients' physical illness and coping. Clinicians are concerned a more rigid “tick-box” approach may inhibit patients and detract from clinical engagement with their problems. Given the low detection rates for depression, it may be the stigma of raising this subject for discussion which is actually behind the reluctance to question the patient more formally.<sup>273</sup>

In response to many of the calls for clarity and standardisation in the assessment of depression in palliative care settings, in 2010, the European Palliative Care Research Collaboration published guidelines on the management of depression in palliative care.<sup>274</sup> The guideline has three main sections: prevention; detection, diagnosis and assessment; and treatment. It notes that high quality palliative care is of itself a key strategy for preventing and alleviating depression at the end of life, citing a study in the *New England Journal of Medicine* which showed that metastatic lung cancer patients who received early palliative care had improved mood and quality of life compared with those receiving standard oncological care.<sup>275</sup>

The guidelines state that depression should be diagnosed according to standardised, validated diagnostic criteria (e.g. ICD-10 or DSM-V). With regard to detection and assessment, the European guidelines state that clinicians should ask about mood as part of routine consultation and assessment. The authors of the guideline note that there is mixed evidence on the ability of screening tools to improve depression outcomes, as the screening may not always lead to appropriate treatment.<sup>276</sup> However, as the screening tools are unlikely to cause any harm to the patient, there is nothing to suggest that they should not be used to aid the detection of depression.

The Brief Edinburgh Depression Scale (BEDS) was developed to briefly and accurately measure depression in those in the advanced stages of cancer. It is a six item test which covers guilt, insomnia, fear, sadness, inability to cope, and thoughts of self-harm. It seeks to address the limitations of other screening tools in detecting depression in terminally ill patients by excluding somatic symptoms and focussing on subjective feelings of worth and sadness. In its brief form, BEDS also has the advantage of being quick and easy to use, which is an important consideration when treating terminally ill patients.<sup>277</sup>

## Treatment

Palliative care seeks to improve the quality of life of dying patients through the early identification, assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. High quality palliative care can help to alleviate many of the distressing emotions associated with the dying process. However, the treatment of depression requires additional interventions. In addition to the general lack of evidence on the prevalence of depression in palliative care populations, there are too few adequate studies to draw clear conclusions about the management of depression in these settings. Many of the studies which do exist focus on the treatment of depression amongst patients with terminal cancer, leading many researchers to suggest further specific research should be carried out into depression in other patient groups.<sup>278</sup>

The European guidelines on the management of depression in palliative care settings state that whilst evidence on the treatment of depression in palliative patients is scarce, there is nothing to suggest that a radically different approach from the “standard” treatment of psychological therapy and anti-depressants is required. As with treatment in all other settings, patients should be consulted on the different treatment options available before commencement, and the treatment should be regularly reviewed. The National Institute for Health and Care Excellence (NICE) has more general guidance on the treatment and management of depression in adults.<sup>279</sup>

Evidence indicates that there is a high remission rate amongst palliative care patients with depression: one study found that two-thirds of their sample who had major depression at the outset of the survey had remitted by the follow-up stage.<sup>280</sup> They note that this high rate could partially be explained by non-participation (17 per cent of the sample did not follow up), but that even if all of those who did not participate remained depressed, the remission rate remained high at 55 per cent. This is striking when compared to remission in other settings – for example, in UK primary care settings, where only 13 per cent of patients with depression were found to have remitted after a month.

Specific pharmacological treatment is unlikely to have accounted for remission, as only a minority of the group who remitted received anti-depressants. The authors suggested a number of reasons for the high remittance rate:

- The higher remittance rate amongst patients receiving palliative care might indicate that high quality palliative care – which includes psychological, spiritual, and social support – can itself alleviate depressive symptoms;
- Low mood at the end of life may be a response to unpleasant physical symptoms (e.g. pain or breathlessness), which disappear when those symptoms are addressed;
- Some palliative care patients who meet the diagnostic criteria for depression may be experiencing transient psychological distress in response to the diagnosis of a terminal illness. Remittance may be spontaneous amelioration of depressive symptoms as patients adjust to and accept their situation.

They noted that “medicating sadness” may cause unnecessary side-effects and impede provision of appropriate support. For some patients presenting with depressed mood, active palliative care with frequent assessment may be a proper alternative to immediate initiation of medication – particularly, they note, if depression is reported shortly after referral to palliative care, which can be a difficult transition time. This is mirrored by the European guidelines on the management of depression, which note that the psychological state of patients receiving palliative care can be unstable, and that clinicians should regularly review depressive symptoms to capture changes in mood.<sup>281</sup>

The authors also concluded that depression in this population is unstable and can fluctuate over time – therefore effective management requires careful monitoring of symptoms and provision of care.

Patients who are experiencing “transient psychological distress” rather than an enduring depressive disorder can still benefit from psychological support and referral to specialist care where appropriate, and the European guidelines on the management of depression in palliative care settings reinforce this.<sup>282</sup>

There is general evidence that as with treating depression in other settings, anti-depressants are effective in treating depression in palliative care. Various studies have noted the general effectiveness of anti-depressants in relieving distress, especially when combined with psychotherapy and/or counselling.<sup>283</sup> A recent multi-centre study in Scotland evaluated the efficacy of an integrated treatment programme for major depression in patients with cancer, which included psychotherapeutic treatment and anti-depressants.<sup>284</sup> Crucially, the treatment was delivered by the oncology team, rather than psychiatrists. It found that, in comparison with cancer patients in “usual care”, participants allocated to the specialist treatment programme had less depression, anxiety, pain, and fatigue; and better functioning, health, quality of life and perceived quality of depression care.

This study was not focussed exclusively on the terminally ill. One of the problems with psychological approaches is that there may not be sufficient time to implement them. It can be difficult to guarantee the whole of a course of treatment when the patient may only have a few weeks to live. Additionally, the use of anti-depressants is often “too little, too late”, with the majority of eligible patients receiving inadequate doses, only initiated within two weeks of their death.<sup>285</sup> A widely cited 1999 study found that terminally ill patients with depression were very often prescribed anti-depressants so late that they often died before the medication had time to take effect.<sup>286</sup> For rapid effect on depressed mood at the very end of life, some doctors are known to use psychostimulants – including those used to treat attention deficit hyperactivity disorder (ADHD).<sup>287</sup>

There are a number of additional issues related to using anti-depressants which are unique to palliative care settings. One study indicated that in comparison to the use of anti-depressants in general physical illness, where the efficacy of anti-depressants was at its highest at 6-8 weeks, in cases of life-threatening illness, the efficacy of anti-depressants increased over time, with the largest effect occurring at 9-18 weeks.<sup>288</sup> The authors of the study concluded that this finding highlighted the need for increased awareness and attention to depression in palliative care so that patients can be diagnosed early and treated promptly with adequate treatment so that they are as mentally well in their last few weeks of life as possible. It also emphasised the need for patients to continue to take anti-depressants, even if there is little effect in the first few weeks.

Other issues relate to the choice of anti-depressants. Some anti-depressants might benefit patients with certain physical conditions – for example, mirtazapine can cause sedation and increased appetite, while tricyclic anti-depressants have been shown to relieve neuropathic pain. Equally, some anti-depressants are contra-indicated for certain conditions or symptoms. For example, tricyclic anti-depressants can adversely affect patients with heart disease or liver failure.<sup>289</sup>

## 8. Depression and pain

It is well-established that pain and depression are related.<sup>290</sup> The precise reasons for this association remain unclear, but may be neurobiological, psychological, and behavioural. Generally, depressed patients report more pain than non-depressed patients.<sup>291</sup> One review of the relationship between depression and pain (not just in palliative settings) found that 65 per cent of patients with depression experienced one or more pain complaints; and that 5 to 85 per cent of patients with pain conditions (depending on the study setting) had symptoms of depression.<sup>292</sup> The same study also noted that the presence of pain negatively affects the recognition and treatment of depression, as patients frequently present only with physical symptoms and rarely connect those symptoms to depression or any other psychiatric condition. As a result, clinicians will treat the physical symptoms medically instead of exploring them in a broader context.

Conversely, pain-free periods have been shown to give patients new strength and lower the incidence of mood disturbances and suicidal ideation.<sup>293</sup> It is therefore important for doctors to consider the relationship between depression and pain when starting treatment for depressed terminally ill patients, and in particular, to reconsider the use or dosage of analgesics. The relationship between pain and depression is so significant that it led to the American College of Physicians/American Society of Internal Medicine Consensus Panel to



state that one of the first steps in assessing and treating depression at the end of life should be to control pain.<sup>294</sup>

## 9. Depression and desire for death

It is common for patients with terminal illnesses to have suicidal thoughts. By some estimates, such thoughts occur in up to 45 per cent of patients with terminal cancer, but are usually fleeting and generally associated with feelings of loss of control and anxiety about the future.<sup>295</sup>

However, in a small number of terminally ill patients there is a sustained and pervasive wish for death to come quickly. Various studies have placed this from anywhere between 1 per cent and 28 per cent of cancer patients, depending on the sample group and the definition of “desire for hastened death” used.<sup>296</sup> A review of cancer patients admitted to palliative care found that a diagnosis of depression was significantly associated with a desire for hastened death, with patients with a major depressive disorder being four times more likely than non-depressed patients to have a high desire for hastened death.<sup>297</sup>

Depression and hopelessness are the strongest predictors of desire for hastened death in terminally ill cancer patients, providing independent and unique contributions.<sup>298</sup> In a separate sample of palliative care patients, 28 per cent of those with depression wished for an early death compared with 7 per cent of non-depressed patients.<sup>299</sup> A Canadian Study of 406 cancer patients found that depression and hopelessness were mutually reinforcing but distinct constructs. Both depression and hopelessness independently predicted the desire for a hastened death, and mediated the effects of psychosocial and disease-related variables on this outcome. The authors concluded that this finding supports a holistic approach to the palliative care of cancer patients, which addresses the psychological and spiritual needs of patients, as well as the physical needs.<sup>300</sup> Some studies have suggested that depression is more influential on the desire to hasten death than physical pain.<sup>301</sup> One study of cancer patients noted that pain severity and the degree to which that pain impaired physical functioning were correlated with a desire for hastened death.<sup>302</sup> Contrary to the authors’ expectations, however, the decline in pain intensity levels over one month was not predictive of improvement in desire for hastened death.

A study into the prevalence of a desire for hastened death in a sample of UK palliative care patients identified a number of positive associations with desire for hastened death, which were the presence of depression, suicidal thoughts, higher scores on measures of fatigue, pain, insomnia and dyspnoea, and hopelessness and a perceived loss of dignity.<sup>303</sup>

The same study, however, found that the prevalence of a desire for hastened death was lower than previous studies had suggested. It found that even amongst patients who express a severe or persistent desire for death (which they noted was rare), this usually remitted over time. Over a third of those who reported *any* desire for death during the initial assessment no longer did so at the second stage assessment, and only one participant maintained a strong desire for death across both time-points. The authors concluded that the provision of effective symptom-control combined with timely detection and intervention for depression were all likely to contribute to the alleviation of desire for hastened death in patients with advanced illnesses. They further noted that these were all interventions which were “within the scope of palliative care services”.

There is varied evidence on whether treatment of depression results in a diminished desire for early death. A study of the effect of depression treatment on elderly patients’ preferences for life-sustaining medical therapy found that in the majority of patients, remission of depression did not result in an increase in desire for life-sustaining treatments.<sup>304</sup> Twenty-six per cent of patients who had been initially rated as more severely depressed, more hopeless, and more likely to overestimate the risks and to underestimate the benefits of treatment, however, showed an increased desire for life-sustaining treatment after their depressive symptoms improved. The authors concluded that in depression of mild to moderate severity, a patient’s desire to forgo life-sustaining medical treatment is unlikely to be altered by depression treatment. On the other hand – reflecting the general

situation where patients with severe depression respond better to anti-depressants than those with less severe depression – severely depressed patients can benefit from treatment, and patients should be encouraged to delay making decisions about refusing life-sustaining interventions until depression has been treated.

A study of treatment for depression on the desire for hastened death in patients with advanced AIDS concluded that successful treatment of depression substantially decreased a desire for hastened death.<sup>305</sup> It found that desire for death was highly associated with depression, and that that desire decreased dramatically in patients who responded to anti-depressant treatment. Little change in desire for hastened death was observed in patients whose depression did not improve.

### Part Three – Prescribing at the end of life in the ‘post-Shipman era’

Timely and appropriate use of pain relief is an essential part of the care of dying patients. As discussed above, pain has been positively associated with depression and a desire for a hastened death and can impact on individuals’ capacity to make decisions about their care and treatment at the end of life. The suggestion that doctors may now be more reluctant to prescribe strong pain relief medication at the end of life than they were in the past – often attributed to ‘the Shipman effect’ – is therefore a matter of significant concern.

## 10. Harold Shipman and the Shipman Inquiry

Harold Shipman was a general practitioner and one of Britain’s most prolific serial killers. Having spent over twenty years practising medicine, he was arrested and convicted in January 2000 of the murder of 15 elderly patients with lethal injections of morphine. Estimates of the true extent of his crimes suggest that he may have killed around 250 of his patients in this way. Harold Shipman killed himself on 13 January 2004, while serving 15 life sentences.

In February 2000, the government ordered a public inquiry into the extent of his crimes; how they went undetected for so long; and what could be done to prevent them from happening again. The inquiry – often referred to as the “Shipman Inquiry” – ran from 2000 to 2005, and was chaired by Dame Janet Smith CBE.<sup>306</sup>

The Shipman Inquiry resulted in the publication of six reports and amounted to a comprehensive review of Britain’s legal structure in relation to healthcare and medicine. The inquiry found major flaws in the processes for the prescription of drugs, monitoring of doctors, and registration of deaths.

The fourth report of the inquiry considered the regulation of controlled drugs in the community and highlighted the instances where both individuals and systems failed to identify Shipman’s actions. It called for measures to prevent doctors from stockpiling drugs in the manner Shipman did.<sup>307</sup> The fifth report of the inquiry criticised the General Medical Council (GMC) and made proposals for the safeguarding of patients.<sup>308</sup> The inquiry contributed significantly to proposals already under discussion for a requirement for all doctors to have their licence to practise revalidated by the GMC every five years, and, most pertinently for the purposes of this section, to the development and implementation of new regulations for controlled drugs (which include morphine).<sup>309</sup>

Following the Shipman Inquiry, the Government outlined its action programme for strengthening the safeguards relating to controlled drugs as *Safer management for controlled drugs*.<sup>310</sup> This was enshrined in sections 17-25 of the Health Act 2006, and in subsequent regulations.<sup>311</sup> The main components of these regulations included requirements for all health organisations to have a named person responsible for the safe management and use of controlled drugs (CDs); to share information about potential CD offences with relevant bodies; and create clearer arrangements for the monitoring and inspection of CDs. Safer management for controlled drugs reports are now published annually by the CQC.<sup>312</sup>

### The 'Shipman Effect'

The crimes of Harold Shipman, and the subsequent inquiry, had a profound effect on medical culture in the UK. Tighter regulation following the inquiry has allegedly led to the 'Shipman effect', a phrase coined by the British media.<sup>313</sup> It has been suggested that some doctors changed their prescribing and dispensing of pain relief medication out of fear of being accused of malpractice, and experiencing professional or criminal sanctions. As recently as December 2014, the BBC reported that the 'Shipman effect' had "changed medical practice forever", causing fear in the medical community and changing the way doctors conduct palliative care.<sup>314</sup> In March 2015, *The Lancet* published an editorial outlining its manifesto for health ahead of the 2015 General Election. The article criticised a number of NHS scandals – and referred specifically to Shipman – which, it was claimed, had created a culture of "blame, fear, and intimidation" in the UK's health system.<sup>315</sup>

Of particular relevance to the debate on end-of-life care and physician-assisted dying is the concern that the aftermath of Shipman has led doctors to be more cautious in their prescribing and dispensing of pain relief medication when patients are nearing the end of their life.

### 11. The doctrine of double effect

There is little evidence that the appropriate use of medication to control pain at the end of life hastens death.<sup>316,317</sup> If analgesics and sedatives are properly titrated against a patient's pain, the risk of respiratory depression is small and they are unlikely to have an effect on a patient's lifespan.<sup>318</sup> Despite this, there are concerns that administering strong analgesics or sedatives at the end of life can, in some cases, hasten the death of a patient. An alternative explanation for this, suggested by some clinicians, is that death can be delayed by the presence of pain, and that when prescribed drugs have made the person comfortable and pain free, natural death can occur. Yet another explanation is that when analgesia is administered in the closing hours of life, the patient's subsequent death is not necessarily the result of that act but a concomitant event – though it may not always be seen as such.

Whatever the clinical reason for this apparent link, in some cases, "the doctrine of double effect" has been used to differentiate, legally and ethically, between the *legitimate* use of strong analgesics or sedatives (in particular opioids) to relieve pain and symptoms at the end of life and the *illegitimate* use of such medication with the intention of hastening death. Under the "doctrine of double effect" a physician may use strong pain relief, even if that might risk hastening death, provided the intention is to relieve the patient's suffering, and the dosage is proportionate to that intention.

In *Medical Ethics Today* the BMA advises that:

"Fears that one's motives may be misinterpreted should not stand in the way of doctors providing good quality symptom control. If the intention is clearly to relieve pain and distress and the dosage is commensurate with that aim, the action is ethical and lawful. Once the patient's pain or distress has been relieved, if the dose is increased without further clinical indication, the doctor's motive in taking this step must be seriously questioned. When doctors are unable to relieve pain and are concerned about increasing the dose further, specialist advice should be sought from the local hospice or palliative care team".<sup>319</sup>

In 2007 Annie Lindsell, who had motor neurone disease, sought a declaration from the court that it would not be unlawful for her GP to administer drugs for the relief of her mental distress when she became unable to swallow. She feared choking episodes and being unable to speak. Her GP had been warned by the Medical Protection Society that he might face a murder charge if he carried out her wishes to medicate her to relieve her distress. She asked the High Court to confirm that mental distress, as well as physical pain, could be treated with medication that could have the incidental effect of shortening her life. The GP said that he was not proposing to "anaesthetise her to death" but he did believe in "forthright and unhesitating relief of distress and pain, with no half measures". Experts in palliative care gave advice that the regime proposed by the GP was in accord with best medical practice. Ms Lindsell withdrew her application after the doctor's plans for her care were supported by

the medical experts; a declaration was therefore not required.<sup>320</sup> This case merely restated the already existing legal position on double effect.

Some physicians have expressed concern that acceptance of the concept of double effect may itself perpetuate the belief that adequate pain management in terminally ill patients will inevitably hasten death, which could act as a deterrent to the provision of good symptom control at the end of life.<sup>321,322</sup> For this reason, whilst it is reassuring for health professionals to have the medico-legal defence provided by the doctrine of double effect, it is important to realise it is not deliberately used in good clinical practice.

## 12. General Medical Council's guidance on pain relief at the end of life

The GMC guidance *Treatment and care towards the end of life* views the offer of pain relief, along with food and drink by mouth, as part of basic care. It states that doctors must:

“give early consideration to the patient’s palliative care needs, and take steps to manage any pain, breathlessness, agitation or other distressing physical or psychological symptoms they may be experiencing”.<sup>323</sup>

It further states that doctors should explain clearly to the patient’s family that, regardless of any decisions made about particular treatments, the patient’s condition will be monitored and managed to ensure that they are comfortable, and as far as possible, free of pain.<sup>324</sup>

## 13. Doctors’ views on prescribing pain relief at the end of life post-2000

There is little published research about the effect that the Shipman case has had on medical practice in palliative care in the UK and, in particular, whether doctors are now exercising greater caution when deciding whether to prescribe strong opioids to help relieve pain and distress. Some authors have suggested that a number of concerns about the use of opioids pre-date the Shipman case.<sup>325</sup> These concerns largely relate to fears, on the part of both doctors and patients, about dependency or misuse, and to perceptions that opioids are only for use at the end of life.

The trade press has, however, highlighted concerns that the unintended consequence of the Shipman Inquiry was that GPs were more reluctant to prescribe strong painkillers,<sup>326,327</sup> and, at least anecdotally, doctors have expressed concerns about providing pain relief at the end of life which have been exacerbated post-Shipman. A survey carried out by the Small Practices Association (SPA) on behalf of BBC Radio 4 indicated that GPs had become more nervous about prescribing opiates to terminally ill patients in case of accidental overdose.<sup>328</sup> The same survey found that a quarter of GPs stopped holding a stock of opiates in their surgeries and one third stopped carrying them.

Some studies have been undertaken into the use of analgesics at the end of life since Shipman’s conviction in 2000. A 2011 study of the use of analgesics in the last three months of life in lung cancer patients found that analgesics are being increasingly prescribed at the end of life in lung cancer – in particular, level 3 analgesics (strong opioids).<sup>329</sup> However, the authors found that analgesics, particularly level 3, were relatively under-prescribed to patients over the age of seventy. They attributed this to a number of reasons, including the fact that the administration of pain relief is a balance of benefits versus harm, which can be harder to strike with older patients since pain management has consistently been found to be more problematic for older people; that older patients may be less likely to report pain than young patients; and that older patients may have atypical manifestations of pain.

The study further noted that there was a “small dip” in analgesic prescribing in primary care between 2003 and 2004, when the Shipman case received widespread attention. The authors suggested that this supports the hypothesis that the Shipman case would adversely affect appropriate opioid prescribing and pain management, but note that it was a short-term effect, and that the upward trend in opioid prescribing continued post 2004.

A 2014 study also found evidence of a small dip in “complex cases” (the use of multiple strong opioids) around the time of Shipman’s suicide in 2004, and subsequent media exposure of the full scale of his crimes.<sup>330</sup> This dip in complex cases contrasted with what they described as a “general increase in background opioid prescribing”. The authors suggested that the Shipman case did not affect the public’s perceptions about or willingness to use opioids as evidenced by the steady increase in patients receiving opioid prescriptions. The authors concluded that there was a need for better training and education to improve the knowledge and attitude of clinicians about opioids.

A similar 2014 study of trends in opioid prescribing in the UK concluded that there has been a “huge increase” in strong opioid prescribing in primary care between 2000 and 2010. Though it was not possible to differentiate between prescriptions to relieve pain at the end of life and those for chronic pain, the study found that morphine was the most frequently prescribed opioid, and that the use of other strong opioids such as oxycodone and fentanyl also increased “markedly” over time.<sup>331</sup>

Qualitative research into the attitudes of health professionals, however, has found more evidence of reluctance amongst clinicians to prescribe opioids at the end of life. A 2012 study identified several barriers to the appropriate use of opioids in end-of-life care – in particular for professionals working in primary care.<sup>332</sup> Many participants reported that GPs were sometimes over-cautious with the use of opioids, and that there was a general reluctance to prescribe high doses. Participants discussed this with explicit reference to Shipman and his crimes as impacting on their willingness to prescribe high doses of opioids. There was general agreement that GPs lacked specialist knowledge regarding appropriate dose management of opioid therapy, and that there was insufficient training available. Participants also suggested that the Shipman case had led to better multi-disciplinary team working and close collaboration between primary care providers and palliative care providers – and that GPs who lacked confidence or expertise in opioid prescribing increasingly sought advice from palliative care professionals. The study also addressed barriers to opioid use from patients and family members, who generally associate opioids with addiction or death. Participants highlighted the importance of good communication with patients and families.

#### **Part Four – How accurate are doctors’ estimates of survival for dying patients?**

Prognosis for survival can affect all levels of decision making around end-of-life care, including social and financial decisions, the timing and referral to palliative care services, and allowing the individual to plan and prepare for dying. Providing accurate estimates of how long a patient has left to live, however, remains a challenge for doctors. This section explores the available research on the accuracy of predicting life expectancy when someone has a terminal condition, and the variety of prognostic tools used by doctors to predict survival.

#### **14. Clinical prediction of survival (CPS)**

Clinical prediction of survival (CPS) is an individual doctor’s estimate of patient survival. CPS is a common method of estimating survival prognosis in terminal illness, and as such, there has been a lot of research conducted into the accuracy of this approach. In 2003, Glare *et al* published a systematic review of research measuring the accuracy of CPS in advanced cancer. The review found that clinicians were accurate in predicting survival (to within one week) in 25 per cent of 1,563 individual prediction-survival cases.<sup>333</sup> Errors in accuracy were generally overestimations of survival rather than underestimations and the median survival time was 29 days (range 13 – 62 days). The review also identified the presence of a “horizon effect” whereby accuracy increased as the length of patient survival decreased. The review concluded that doctors tend to be incorrectly over optimistic when estimating the time an individual will live when actual survival is around two months, but that clinician accuracy may improve the closer an individual is to death.

A study published prior to this review that measured CPS accuracy across four multi-professional palliative care teams in England found that CPS was accurate in 42 per cent of cases, over optimistic in 36 per cent of cases and over-pessimistic in 22 per cent of cases.<sup>334</sup> The mean patient survival in this study was 71 days (range one to 734 days). This suggests that similar to the results published by Glare *et al*, clinicians in palliative care teams in

England tend to be inaccurate in predicting survival when actual survival is around two to three months, and they are more likely to overestimate than underestimate survival time. In addition, the authors of this study reported a horizon effect in their data, whereby CPS accuracy was found to increase to 70 per cent when survival time was less than 14 days.

In a study published in 2011, CPS accuracy was measured across specific prognostic time-points (< 24 hours, one to seven days, one to four weeks, one to three months, three to six months, three to 12 months and > 12 months) and found that doctors' accuracy was significantly higher when predicting that a patient had less than 24 hours (approximately 80 per cent accuracy) and one to seven days (approximately 67 per cent accuracy) to live in comparison to all other time points of survival that were predicted (one week to 12 months).<sup>335</sup> This suggests that when predicted survival is around one week or less, doctors have the greatest chance of providing an accurate estimate of survival. The study also found that clinician accuracy was significantly lower when predicted survival ranged between one and 12 months (see Figure 4 below). This indicates that doctors may only have around a one in five chance of accurately predicting survival where an individual has between one and 12 months to live. Furthermore, these data indicate that doctors may be up to three times more likely to incorrectly overestimate the length of time an individual may live when predicting survival times of between one and 12 months. Interestingly, CPS accuracy significantly increased when a patient was predicted to have more than 12 months to live and accuracy for predicted survival at this time point was similar to that for one to four weeks (approximately 40 per cent). This suggests that doctors might have a better chance of accurately predicting survival if an individual has more than one year to live, although there is still a considerable amount of error associated with these predictions (60 per cent over-estimation).

The overall pattern of CPS accuracy with greater than 12 months' survival time indicates that doctors may be the most accurate in predicting survival the closer an individual is to death (horizon effect) and the most inaccurate when an individual has between one and 12 months to live. Accuracy may increase slightly if an individual has one year to live, but predictions for this survival time are still no more accurate than a fifty-fifty chance.

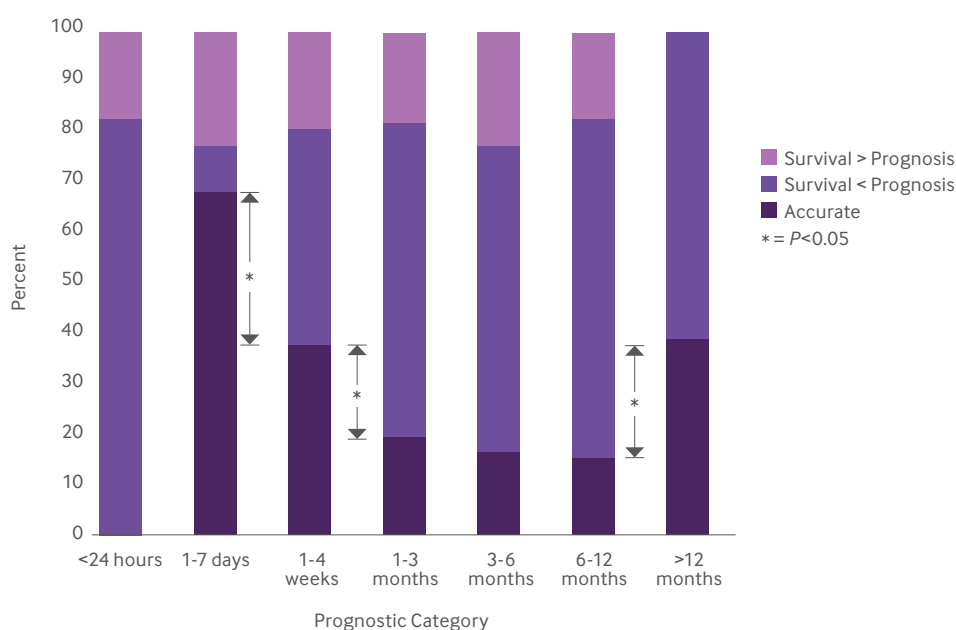


Figure 4 – Distribution of CPS accuracy by time-based prognostic category (n = 1835). Taken from Selby D, Chakraborty A, Lilien T et al. "Clinician accuracy when estimating survival duration: the role of the patient's performance status and time-based prognostic categories." *J Pain Symp Manage* 2011; **42**(4): 578-588. [Redrawn with permission.]

It is also noteworthy that the patient cohort used in this study consisted of terminally ill cancer (80 per cent) and non-cancer (20 per cent) patients. As individuals with non-cancer terminal illness are historically under-researched in this area, the results of this study are useful for considering the accuracy of clinicians' survival estimates for both cancer and non-cancer populations. A 2000 study conducted by Christakis *et al* also measured the accuracy of CPS in a cohort of non-cancer (35 per cent) and cancer (65 per cent) patients. The results of this study similarly found that doctors had poor accuracy in estimating patient survival (20 per cent) and that doctors over-estimated patient survival by a factor of 5.3 (63 per cent of doctors' predictions were over-optimistic, compared to 17 per cent which were over-pessimistic).<sup>336</sup> The study indicated that prognostic errors were common to most types of doctors, in most types of patients. It noted, however, that the tendency of doctors to make prognostic errors was lower amongst experienced doctors; but that the better the doctor knew the patient and the stronger the relationship, the more likely they were to err.

The results of these studies also draw attention to the lack of research that specifically addresses accuracy of CPS for non-cancer terminal illness.

### Temporal vs probabilistic CPS accuracy

The approach described above – where a clinician estimates the length of time that an individual will live with no variation in the probability of this estimate, for example, “four weeks” – is referred to as “temporal CPS”. An alternative approach is “probabilistic CPS”, which describes a doctor's estimate of the probability that an individual will be alive at a fixed time-point, for example, a “90 per cent chance of being alive at four weeks”.

Two studies have shown that probabilistic CPS is significantly more accurate than temporal CPS in predicting survival prognosis amongst advanced cancer patients. A study published in 2011 by Hui *et al* -assessing CPS in a limited cohort of eight physicians and twenty nurses - found that the accuracy of probabilistic CPS ranged between 56 and 96 per cent across prognostic time-points from greater than 24 hours to six months, whereas temporal CPS by the same clinicians was only accurate in 32 per cent of cases.<sup>337</sup> A separate study, by Perez-Cruz *et al*, indicated that when the accuracy of temporal and probabilistic CPS for terminal cancer patients was compared during the last 14 days of life, the accuracy of probabilistic CPS decreased, indicating that this method becomes more inaccurate the closer an individual is to death.<sup>338</sup> The authors concluded that the accuracy of probabilistic CPS is consistently higher than temporal CPS, although its accuracy decreases the closer the patient is to death. Temporal CPS, meanwhile, is consistently low in accuracy, but does not change over time; contrasting with previous studies reporting a horizon effect for CPS accuracy.

Overall, these data suggest that probabilistic CPS may be more helpful in predicting survival in cancer patients in comparison to temporal CPS, but that the accuracy of this approach rapidly declines during the final days of survival in advanced cancer.

## 15. Tool-based methods of prognosis

A number of factors that are individually associated with survival, including performance status, specific disease symptoms and laboratory variables, have been collated into prognostic tools to help aid doctors to estimate survival in terminal illness. There are a number of different prognostic tools that have been developed both for disease-specific and non-disease specific survival prediction. A 2007 systematic review of prognostic tools used in palliative care found that the most established tools are the PaP (palliative prognostic score) and PPI (palliative prognostic index).<sup>339</sup> The review concluded that there is an overall lack of validation across diseases, care settings, researchers and clinicians amongst prognostic tools currently available. Even the most established prognostic tools identified, such as PaP and PPI, require further validation across cancer and non-cancer patients in different care settings.

The PaP measures performance status (Karnofsky performance score), disease symptoms (dyspnoea, anorexia), CPS and laboratory measures (total white blood count and lymphocyte count) to generate a combined score between 0 and 17.5. Scores are grouped into three categories that represent different probabilities of survival at 30 days (score 0 – 5.5 = > 70

per cent of survival (group A); score 5.6 – 11.0 = 30 – 70 per cent chance of survival (group B); 11.1 – 17.5 = < 30 per cent chance of survival (group C)). The discriminative accuracy of PaP has been validated across different populations (hospital, palliative care unit, acute care) and cancer and non-cancer populations.<sup>340,341,342,343,344,345,346,347</sup> The accuracy of PaP to predict actual length of survival within these different populations, however, is less clear. For example, one study conducted with cancer and non-cancer patients reported that the median survival time for patients in group A (PaP score 0 – 5.5) was 60 days<sup>348</sup> whilst another study conducted solely with cancer patients reported median survival for group A of 142 days.<sup>349</sup> This type of discrepancy demonstrates that whilst PaP can be used to group individuals approaching death into three general categories of survival probability, this cannot be used to translate into actual survival time for an individual, particularly for those individuals that fall into group A with a “good” chance of survival over one month.

In addition to variation in the actual survival times between the three prognostic categories used by PaP, there are also indications that PaP may be less accurate at discriminating between groups A and B. For example, Glare *et al* found that the 30 day survival rate for these groups were 66 and 54 per cent, respectively, whilst the survival rate for group C was 5 per cent.<sup>350</sup> This suggests that PaP may be better for determining those with a ‘poor’ chance of survival to 30 days, it does not discriminate adequately between those with ‘good’ and ‘intermediate’ chance of survival at 30 days.<sup>351</sup> When PaP is directly compared to CPS it has been found to improve doctors’ accuracy in survival estimates at 30 days by approximately 12 per cent (CPS alone 75.6 per cent vs PaP 88 per cent).<sup>352</sup>

The PPI is a prognostic tool that has been specifically developed for cancer that includes performance status (Karnofsky performance score), oral intake, oedema, dyspnoea and delirium. PPI differs from PaP by not including CPS into the overall score, making it more objective. PPI scores range from 0 to 15 and the greater the score the lower the estimated survival time. PPI has demonstrated 84 per cent accuracy when predicting survival shorter than three weeks (cut off score > 6) and 78 per cent accuracy when predicting survival shorter than six weeks (cut-off score > 4) in a cohort of Italian patients whose median survival time was 22 days (95% CI 19-24).<sup>353</sup>

A Japanese hospice study directly compared PPI to doctors’ estimates of survival at three and six weeks; PPI improved prognostic accuracy by approximately 11 per cent;<sup>354</sup> however, there is still a significant error rate associated with PPI when predicting survival at these time points. Morita *et al* found that PPI yielded 16 per cent error (defined as incorrect survival prediction by at least 28 days) when predicting three and six week survival whilst doctors’ estimates yielded 27 per cent error.<sup>355</sup> This suggests that PPI can improve physicians’ ability to predict survival of terminally ill cancer patients in comparison to doctors’ estimates alone but that the chance of associated error with these predictions is still considerably high. Furthermore, when PPI estimates are compared to CPS at 30 days (approximately four weeks), PPI is actually less accurate than clinicians’ estimates alone (72.3 vs 75.6 per cent), leading some authors to conclude that PaP is more useful when a more accurate prognostication is needed, but that other scores can be used when a rapid and simple evaluation is sufficient.<sup>356</sup>



More recently, the PiPS (prognosis in palliative care study) model has been developed and validated amongst a cohort of 1,018 advanced cancer patients in England. PiPS uses a combination of performance status and laboratory variables (when available) to predict the chance of survival at two weeks or two months in advanced cancer. The PiPS-A model does not require laboratory variables obtained from blood tests (for when it is not appropriate to obtain this from a patient) whilst the PiPS-B model does include markers obtained from blood results. Overall, both models have demonstrated accuracy in predicting patients with two week and two month survival.<sup>357</sup> PiPS-A predictions have been found to be approximately 60 per cent accurate and are as accurate as doctors' survival estimates (accuracy 56.3 per cent). The PiPS-B model has, however, been shown to be more accurate than doctors' estimates (61.5 vs 52.6 per cent). This suggests that whilst the PiPS-A and B models can accurately discriminate between cancer patients with two week or two month survival in care settings where blood results may or may not be available, only the PiPS-B model might significantly improve the accuracy of clinicians estimates of survival.

In regards to non-cancer prognostic tools, the HFRSS (heart failure risk scoring system) can accurately separate individuals with a recent history of heart failure into risk categories with an associated mortality chance at 30 days and 1 year (Table 4).<sup>358</sup> From Table 4 it can be seen that a high HFRSS score indicates approximately 50 per chance of mortality at 30 days and 75 per cent chance of mortality at one year. However, whilst both of these tools are useful for estimates of risk that may assist clinicians, patients and families in clinical decision making, neither tool would allow one to establish the survival time of an individual within these stages. Furthermore, the HFRSS has also only been validated in one study, meaning the accuracy of the model to predict mortality across different populations and care settings is unknown.

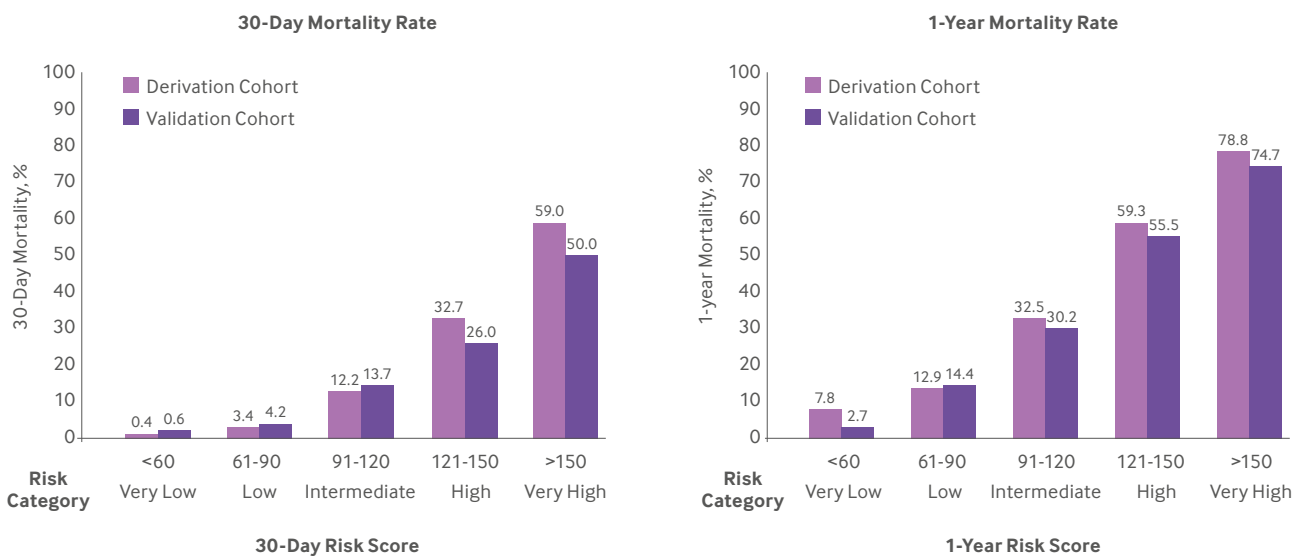


Table 4: Mortality rates at 30 days and one year relative to risk scores. Taken from Lee DS, Austin PC, Rouleau JL et al. "Predicting mortality among patients hospitalized for heart failure: derivation and validation of a clinical model." JAMA 2003; 290(19): 2581-2587.

The SHF (Seattle heart failure) model uses clinical data to predict the likelihood of survival in chronic heart failure patients at one, two and five years. This model has been validated in over 10,000 patients but when recently applied to a community-based cohort of chronic heart disease patients in the UK the model only predicted 12 per cent of those who were in the last year of life indicating significant under-estimation of 12 month mortality.<sup>359</sup> This study also tested the accuracy of the GSF (gold standard framework) prognostic indicator guide in this cohort of chronic heart disease patients and similarly found that the GSF had poor prognostic accuracy. However, in contrast to the SHF, the GSF greatly overestimated the number of patients in the last year of life. These data highlight the poor prognostic ability of models to predict survival time in patients with chronic heart failure.

### **Summary of the accuracy of prognostic tools**

There are currently a number of prognostic tools that have been developed that may improve the accuracy of predicting survival of terminally ill patients above that of a doctor's estimate alone. There are, however, a number of common limitations associated with these tools in relation to the question of prognostic accuracy of survival at six months or less. First, there is no tool currently available that can provide an accurate estimate of survival throughout the spectrum of advanced illness. There are some tools that may improve prognostic accuracy above that of CPS when the actual survival time of an individual is at or less than two months (PaP, PPI, PiPS); however, there is still a considerable error and inadequate validation associated with many of these tools. This means that the reliability of these tools to accurately predict survival time across different patient populations, care settings and clinicians is unknown. Secondly, the development and validation of prognostic tools have largely focussed on advanced cancer. This may be because cancer has a more predictable disease trajectory in comparison to non-cancer disease, whereby there is a steady period of decline followed by a sudden period of rapid deterioration before death in comparison to intermittent periods of rapid deterioration and recovery in non-cancer disease.<sup>360</sup> However, it remains the case that even amongst those tools that fall under the category of 'non-disease specific' such as the PaP, there has been less validation of this tool amongst non-cancer patients in comparison to cancer patients. Thirdly, the calculations of accuracy within the prognostic tools discussed are based on model (population) estimates that do not necessarily equate to accuracy at an individual level. This means that while prognostic tools may be useful rough guides for estimating predicted survival time, they are not appropriate to use under conditions where accuracy for a specific individual's prognosis is required.



## Chapter 3

# The debate on assisted dying in the UK

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### The debate on assisted dying in the UK

Physician-assisted dying is unlawful in the United Kingdom. In recent years, however, there have been several legal challenges requesting both physician-assisted suicide and euthanasia, and legislative attempts to change the law to permit physician-assisted suicide. In order to design the events for this project, it was crucial for us to have a detailed understanding of the current legal and political context in the UK. The following sections in this chapter consider the law in the UK in relation to assisted dying, setting out how it has developed through key cases, and detailing the most recent legislative proposals considered in England and Wales, and Scotland.

This section also brings together available qualitative and quantitative research to provide a general overview of the research on medical and public views on a range of issues around assisted dying. Whilst the events carried out as part of this project were focussed on specific issues, and did not assess support for or opposition to assisted dying, for completeness, this chapter includes surveys which do so.

#### Part One – Development of the law on assisted dying

##### 1. England and Wales

Assisting another person's death is prohibited in England and Wales by s.2 of the Suicide Act 1961, as amended by the Coroners and Justice Act 2009, which states that any person who "encourages or assists the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction to imprisonment for a term not exceeding fourteen years".

Actions that could be interpreted as assisting, facilitating, or encouraging a suicide attempt may include advising patients on what constitutes a fatal dose; advising patients on anti-emetics in relation to a planned overdose; suggesting the option of suicide abroad; and writing medical reports specifically to facilitate assisted suicide abroad. Further information for doctors about responding to patient requests for assisted suicide can be found on the BMA website<sup>361</sup> and in the General Medical Council's publication *When a patient seeks advice or information about assistance to die*.<sup>362</sup>

Prosecution for such an offence requires the agreement of the Director of Public Prosecutions (DPP), whose role has subsequently been clarified by a number of high profile legal cases.

##### Diane Pretty

Diane Pretty (spelt as Dianne in some court documentation) was diagnosed with motor neurone disease in 1999. Her condition deteriorated rapidly until she became paralysed from the neck down and unable to speak. She repeatedly expressed her wish for "a quick death, without suffering, at home, surrounded by family".<sup>363</sup> She feared her death would be frightening and distressing and wished to avoid this by ending her life at the time of her choosing. Her husband was willing to help her commit suicide, but this would risk him being prosecuted under the Suicide Act 1961. She sought an undertaking from the DPP that, if her husband aided her, he would not be prosecuted.

Mrs Pretty made the following claims related to her rights under the European Convention on Human Rights (ECHR):

- The Article 2 right to life protected a right to self-determination, entitling her to commit suicide with assistance;
- Failure to alleviate her suffering by refusal of the undertaking amounted to inhuman and degrading treatment prohibited by Article 3;
- Her rights to privacy and freedom of conscience under Articles 8 and 9 were being infringed without justification; and
- She had suffered discrimination in breach of Article 14, since an able-bodied person might exercise the right to suicide whereas her incapacities prevented her from doing so without assistance.

The Law Lords unanimously dismissed her appeal, finding that Article 2 could not be interpreted as conferring a right to self-determination in relation to life and death and assistance in choosing death. The court also held that the DPP had no power to undertake that a crime yet to be committed should be immune from prosecution, as the DPP could not dispense with or suspend laws without parliamentary consent.<sup>364</sup>

Five months later, the European Court of Human Rights (ECtHR) unanimously ruled that neither the blanket ban on assisted suicide, nor the DPP's refusal to give an advance undertaking that no prosecution would be brought against Mrs Pretty's husband, infringed her Article 2 or Article 3 rights under the ECHR. Specifically, "no right to die, whether at the hands of a third person or with the assistance of a public authority can be derived from Article 2 of the Convention".<sup>365</sup>

The European Court, however, did recognise that in the face of growing technological sophistication in medicine, some patients would choose not to have their lives prolonged by it, but that in Mrs Pretty's case, she was "prevented by law from exercising her choice to avoid what she considers will be an undignified and distressing end to her life".<sup>366</sup> In other words, the Court was not prepared to exclude the possibility that this interfered with her Article 8 right to respect for her private life. However, they concluded that the UK's blanket ban on assisted suicide was not disproportionate, as it was "necessary in a democratic society for the protection of the rights of others".<sup>367</sup>

Less than two weeks after the ECtHR's ruling in May 2002, Diane Pretty died in a hospice.

### Debbie Purdy and the DPP guidance

Debbie Purdy was diagnosed with primary progressive multiple sclerosis in 1995, and by 2001 was confined to a wheelchair. She said that when her condition became unbearable, she wanted to be able to die at a time of her choosing. Her husband said he was willing to help her, and face a prison sentence for doing so. She was not prepared to put him in that position. In contrast to Diane Pretty, she did not bring legal action to seek immunity from prosecution for her husband. Instead, she sought a declaration that the DPP should be required to publish an offence-specific policy outlining the circumstances in which a prosecution under s.2 of the Suicide Act 1961 would or would not be appropriate.

Ms Purdy lost her case at the High Court and Court of Appeal, but won her appeal to the Law Lords in 2009.<sup>368</sup> The Law Lords considered that the right to respect for private life under Article 8(1) of the ECHR was engaged in Ms Purdy's case. Under Article 8(2), any interference with the right to a private life must be "in accordance with the law" and "necessary in a democratic society in the interests of national security, public safety or... economic wellbeing". Lord Hope held that this principle required the law in question to be "sufficiently accessible to the individual who is affected by the restriction, and sufficiently precise to enable him to understand its scope and foresee the consequences of his actions so that he can regulate his conduct without breaking the law".<sup>369</sup>

The Law Lords held that the DPP had not set out “sufficiently clear or relevant guidance”<sup>370</sup> as to how the discretion to prosecute would be exercised. Accordingly, they ordered the DPP to develop offence-specific guidance on the facts and circumstances to be taken into account in deciding whether to prosecute an offence under s.2 of the Suicide Act 1961.

Debbie Purdy died at the age of 51, on 23 December 2014, in Bradford’s Marie Curie Hospice.<sup>371</sup>

#### *DPP’s guidance*

Subsequent to the Court’s ruling, the then DPP Keir Starmer QC published the *Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide* in 2010 after wide consultation.<sup>372</sup> The policy sets out guidelines for prosecutors when considering whether or not it is in the public interest to prosecute suspected cases of assisted suicide, and lists a number of public interest factors in favour of, and against, prosecution. These factors are set out in full in the text box below.

Section 43.14 specifically addresses the involvement of medical professionals, and states that a prosecution is more likely to be required if “the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer [whether for payment or not], or as a person in authority, such as a prison officer, and the victim was in his or her care”.

A footnote to clarify this section was subsequently added following “Martin’s” appeal to the Supreme Court, explored in more detail below.

As of October 2015, since the publication of the policy, there have been 117 cases of assisted suicide referred to the CPS by the police.<sup>373</sup> Of those cases, 75 were not proceeded with by the CPS and 24 were withdrawn by the police. Six cases were referred onwards as prosecution for homicide or other serious crime. In addition, there were six ongoing cases and one successful prosecution in October 2013. This case involved neither a medical professional, nor a victim with a medical condition.<sup>374</sup>

Public interest factors tending in favour of and against prosecution in suspected cases of assisted suicide <sup>375</sup>	
Public interest factors tending in favour of prosecution	Public interest factors tending against prosecution
<ul style="list-style-type: none"> <li>– The victim was under 18 years of age.</li> <li>– The victim did not have the capacity (as defined by the Mental Capacity Act 2005) to reach an informed decision to commit suicide.</li> <li>– The victim had not reached a voluntary, clear, settled and informed decision to commit suicide.</li> <li>– The victim had not clearly and unequivocally communicated his or her decision to commit suicide to the suspect.</li> <li>– The victim did not seek the encouragement or assistance of the suspect personally or on his or her own initiative.</li> <li>– The suspect was not wholly motivated by compassion: for example, the suspect was motivated by the prospect that he or she or a person closely connected to him or her stood to gain in some way from the death of the victim.</li> <li>– The suspect pressured the victim to commit suicide.</li> <li>– The suspect did not take reasonable steps to ensure that any other person had not pressured the victim to commit suicide.</li> <li>– The suspect had a history of violence or abuse against the victim.</li> <li>– The victim was physically able to undertake the act that constituted the assistance himself or herself.</li> <li>– The suspect was unknown to the victim and encouraged or assisted the victim to commit or attempt to commit suicide by providing specific information, via, for example, a website or publication.</li> <li>– The suspect gave encouragement or assistance to more than one victim who were not known to each other.</li> <li>– The suspect was paid by the victim or those close to the victim for his or her encouragement or assistance.</li> <li>– The suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer (whether for payment or not), or as a person in authority, such as a prison officer, and the victim was in his or her care*.</li> <li>– The suspect was aware that the victim intended to commit suicide in a public place where it was reasonable to think that members of the public may be present.</li> <li>– The suspect was acting in his or her capacity as a person involved in the management or as an employee (whether for payment or not) of an organisation or group, a purpose of which is to provide a physical environment (whether for payment or not) in which to allow another to commit suicide.</li> </ul> <p><i>*For the avoidance of doubt the words “and the victim was in his or her care” qualify all of the preceding parts of this paragraph [43.14]. This factor does not apply merely because someone was acting in a capacity described within it: it applies only where there was, in addition, a relationship of care between the suspect and the victims such that it will be necessary to consider whether the suspect may have exerted some influence on the victim</i></p>	<ul style="list-style-type: none"> <li>– The victim had reached a voluntary, clear, settled and informed decision to commit suicide.</li> <li>– The suspect was wholly motivated by compassion.</li> <li>– The actions of the suspect, although sufficient to come within the definition of the offence, were of only minor encouragement or assistance.</li> <li>– The suspect had sought to dissuade the victim from taking the course of action which resulted in his or her suicide.</li> <li>– The actions of the suspect may be characterised as reluctant encouragement or assistance in the face of a determined wish on the part of the victim to commit suicide.</li> <li>– The suspect reported the victim’s suicide to the police and fully assisted them in their enquiries into the circumstances of the suicide or the attempt and his or her part in providing encouragement or assistance.</li> </ul>



### Tony Nicklinson

Tony Nicklinson suffered a catastrophic stroke at the age of 51, which left him with locked-in syndrome, able only to communicate by moving his eyes. A formerly active man, Nicklinson was confined to a wheelchair and unable to continue his daily life without constant attention from family and carers. He had wanted to end his life for many years following the stroke, but was unable to do so without assistance. He died in August 2012, a week after an unsuccessful appeal to the High Court, where he sought a declaration that would enable him to end his life with assistance. He had contracted pneumonia, and since the verdict, had refused food. His widow, Jane, pursued his appeal to the Supreme Court and was joined by former builder Paul Lamb, who had been left severely paralysed and in need of 24-hour care in a car accident in 1990. Together they sought a declaration that the current law on assisted dying was incompatible with their Article 8 rights under the ECHR.<sup>376</sup>

#### *Supreme Court*

After a near-record six months of deliberation, the Supreme Court (which took over the role of the Law Lords in the House of Lords) rejected the appeal in the cases of Tony Nicklinson and Paul Lamb by a majority of seven to two. A key issue was whether the court had the constitutional authority to make a declaration that UK law on this matter was incompatible with the European Convention on Human Rights. A narrow majority of Justices (five to four) held that it did; the remainder held that the issue was “inherently legislative”<sup>377</sup> and should be left to Parliament to decide. Of those five in the majority, only two considered that the courts should make a declaration of incompatibility at this time.

Several Justices made it clear that Parliament should consider the issue and noted that the Assisted Dying Bill, then due to have its Second Reading in the House of Lords in July 2014, created a timely opportunity for this discussion to take place.<sup>378</sup> The Court further reserved the right to make a future declaration of incompatibility if Parliament failed to address the issue, with Lord Neuberger stating that Parliament must act in the knowledge that “if it is not satisfactorily addressed, there is a real prospect that a further, and successful, application for a declaration of incompatibility may be made”.<sup>379</sup>

#### *European Court of Human Rights*

Mrs Nicklinson and Mr Lamb appealed to the European Court of Human Rights (ECtHR), but in July 2015, their applications were rejected as inadmissible.

Mrs Nicklinson wished to contend that in ruling that they would not make a declaration of incompatibility, the domestic courts had not considered the substance of the claim, and failed to determine the compatibility of UK law with her and her husband’s Article 8 rights to family and private life. The ECtHR concluded that this application was “manifestly ill-founded”.<sup>380</sup> There was nothing in Article 8 which required domestic courts to examine the merits of a complaint regarding primary legislation, and to do so would “have the effect of forcing upon them an institutional role not envisaged by the domestic constitutional order”.<sup>381</sup> Regardless of that fact, the ECtHR held that the Supreme Court had in fact dealt with the substance of Mrs Nicklinson’s claim, and the fact that they attached considerable weight to the views of Parliament did not mean that they had failed to consider it in a balanced manner.

Separately, Mr Lamb argued that the failure of the UK courts to provide him with the opportunity to obtain court permission to allow a volunteer to help him end his life was a violation of his rights. His application was declared inadmissible on the basis that he had not exhausted the domestic remedies available to him: at the Supreme Court, he had only argued that the prohibition on assisted dying infringed his Article 8 rights, not that there should be a judicial process to authorise assisted suicide in some circumstances.<sup>382</sup>

### “Martin”

In the Supreme Court, Jane Nicklinson and Paul Lamb were joined in their appeal by an individual known only as Martin.

Martin had suffered a brainstem stroke in August 2008, which left him paralysed, unable to speak, and only able to communicate using a computer which detected his eye movements. He wished to travel to Dignitas in Switzerland to end his life, but neither his wife, nor other members of his family would provide him with this assistance. He therefore sought an order that would compel the DPP to modify the 2010 policy on prosecution, so as to permit a health or social care professional to accompany him to Switzerland.<sup>383</sup>

Martin’s claim had succeeded partially in the Court of Appeal where it was held that the 2010 policy was not sufficiently clear in relation to healthcare professionals. However, the Supreme Court allowed the appeal brought by the DPP and dismissed the cross-appeal brought by Martin. They held that any lack of clarity in the DPP’s policy did not arise from the published policy itself, but from the discretionary nature of the DPP’s decision to prosecute, and the variety of relevant factors to be weighed in each case. These are all “proper and constitutionally necessary features”<sup>384</sup> of a system of prosecutorial discretion. The Court also noted that whilst the courts had the power to decide that the DPP must publish a policy, it would be entirely inappropriate to dictate what that policy should be. However, the Court was very clear that if there was any confusion as to the policy, the DPP must take steps to clarify this.<sup>385</sup>

#### *Update to the DPP’s guidance*

In October 2014, the new DPP Alison Saunders, issued an update to the 2010 policy to clarify the position on the likelihood of prosecution of a healthcare professional. Section 43.14, which states that prosecution may be required where the suspect was acting in his or her capacity as a medical doctor and the victim was in his or her care, was amended with a new footnote which states that:

*“For the avoidance of doubt the words ‘and the victim was in his or her care’ qualify all of the preceding parts of this paragraph. This factor does not apply merely because someone was acting in a capacity described within it: it applies only where there was, in addition, a relationship of care between the suspect and the victim such that it will be necessary to consider whether the suspect may have exerted some influence on the victim”.*<sup>386</sup>

Many media outlets interpreted this as meaning that doctors who help severely disabled or terminally ill individuals, who are not their own patients, to end their lives are less likely to be prosecuted than those who have an existing relationship of care.<sup>387,388</sup> The DPP, however, emphasised that assisting or encouraging suicide remains illegal, and that nothing in the updated guidance offers immunity from prosecution.<sup>389</sup>

#### *High Court Claim*

In July 2015, Martin took another claim to the High Court, where he sought a declaration that the General Medical Council’s (GMC) guidance on assisted dying interfered with his right to a private and family life under Article 8 of the ECHR and his Article 10 right to freedom of expression, as it prevented him from receiving proper medical advice.

The GMC guidance for doctors on responding to patients who seek advice or information about assistance in dying states that doctors should be prepared to listen and discuss the reasons, but must not breach the Suicide Act 1961 by actively encouraging or assisting.<sup>390</sup> However, in order to access the services of Dignitas as he wished, Martin required a doctor’s report outlining his medical history, including diagnosis and prognosis. Such a report would be likely to breach the GMC’s guidance.

The High Court rejected his appeal, ruling that any interference with his rights was justified. Lord Justice Elias stated that “it cannot possibly be contrary to Article 8 for the GMC to take as its starting point the principle that a doctor has a duty to obey the law, and to structure its guidance accordingly”.<sup>391</sup> Additionally, it was not the function of the guidance to tell doctors “when they can break the law without realistic risk of fitness to practise proceedings, and the courts could not possibly require the GMC to fashion its guidance that way”.<sup>392</sup> Martin has indicated that he will appeal against the decision.

## 2. Scotland

In Scotland, homicide law covers euthanasia, but there is some uncertainty as to assisted suicide. In contrast to the law in England and Wales, assisting another person to die is not an explicit criminal offence. Someone who assists another person to commit suicide could be prosecuted under homicide law. In a letter to MSPs ahead of the debate on the Assisted Suicide (Scotland) Bill in 2015, the Lord Advocate, Frank Mulholland QC, stated that “if someone assisted another to take their own life, such cases would be reported to the procurator fiscal as a deliberate killing of another and it would be dealt with under the law relating to homicide”.<sup>393</sup>

The decision of whether to prosecute someone for homicide is made on the basis of whether there is sufficient evidence to establish that an offence has been committed, and then whether prosecution is in the public interest. The criteria for deciding whether prosecution is in the public interest are set out in the Crown Office and Procurator Fiscal Service (COPFS) Prosecution Code, and include factors such as the attitude of the victim; the motive for the crime; and any mitigating circumstances.<sup>394</sup> Unlike in England and Wales, the COPFS has not issued specific guidance on prosecuting assisted suicide. Speaking at the time of publication of the DPP’s policy for prosecuting assisted suicide in England and Wales, Scotland’s then Lord Advocate, Elish Angiolini QC, said that it would be “inappropriate” to publish detailed guidance.<sup>395</sup>

In his written submission to the Assisted Suicide (Scotland) Bill, the Lord Advocate further stated that there is a high public interest in prosecuting all aspects of homicide where there is sufficient, credible, and reliable evidence. However, every case will be considered on its own facts and circumstances.<sup>396</sup>

As of 2015, the latest prosecution of this type happened in 2006, when the brother of a man with Huntington’s disease was “convicted and admonished” for homicide after assisting in his death.<sup>397</sup>

### Gordon Ross

Gordon Ross, a 66-year-old man from Glasgow, suffers from several medical conditions including Parkinson’s disease, and a loss of sensation in his arms and legs. As a result, he is confined to a wheelchair and is unable to feed or dress himself. In May 2015, he took a case to the Court of Session seeking judicial review of the failure of the Lord Advocate to adopt and publish a policy identifying the factors to be taken into account when prosecuting assisted suicide in Scotland.<sup>398</sup>

Similar to the arguments advanced in *Purdy*, Mr Ross argued that the current COPFS guidance was insufficiently clear and precise so as to enable individuals seeking assisted suicide to foresee the potential liability of whoever assisted them, and that this amounted to an unjustified interference with the Article 8 right to private life under the ECHR.<sup>399</sup>

Mr Ross’s case was dismissed in September 2015 by Lord Doherty in the Court of Session, who held that the Lord Advocate could not be required to promulgate an offence-specific policy for assisted suicide. In his view, the current Prosecution Code was in accordance with the law: “The public know what his policy is and there is no suggestion that it is being applied inconsistently... decisions whether to prosecute will not be based upon the respondent’s

ungoverned whim but will represent conscientious decisions made by him with reference to his policy".<sup>400</sup> He concluded that the policy "does not lack the requisite accessibility or foreseeability. Nor is it arbitrary. It satisfies all the requirements of legality identified in *Purdy*".<sup>401</sup>

Mr Ross has indicated his intention to appeal against the decision.<sup>402</sup>

### 3. Northern Ireland

Assisting another person's suicide is illegal in Northern Ireland by virtue of s.13 of the Criminal Justice (Northern Ireland) Act 1966, which extended s.2 of the Suicide Act 1961. As in England and Wales, the Public Prosecution Service (PPS) examines individual cases to ascertain whether a prosecution should be brought. The DPP for Northern Ireland published definitive guidance for prosecutors in February 2010, very closely modelled on the guidance issued by the DPP for England and Wales at the same time.<sup>403</sup>

#### Part Two: Legislative attempts

In addition to the various legal challenges outlined above, there have been a number of legislative attempts to change the law on assisted dying.

Most recently, the parliamentary year 2014-15 saw legislation on assisted dying under consideration in both England and Scotland. The Assisted Dying Bill, a private member's bill introduced by Lord Falconer of Thoroton, reached committee stage in the House of Lords in January 2015 before it fell when Parliament prorogued for the 2015 General Election. All bills must be agreed by majorities in both Houses of Parliament, and private members bills rarely become law without government support.

The Assisted Suicide (Scotland) Bill, introduced into the Scottish Parliament by Margo MacDonald MSP initially, and taken forward by Patrick Harvie MSP following her death, was rejected by MSPs after debate in May 2015.

In June 2015, Labour MP Rob Marris, who topped the ballot for private members' bills introduced a bill on assisted dying into the House of Commons. The Bill received its Second Reading on 11 September 2015, where it was rejected by a large majority of MPs.

The Bills that have been considered in Westminster would apply only to England and Wales. There are currently no attempts to change the law in Northern Ireland.

### 4. England and Wales

A table comparing the proposals of the bills recently considered in the UK can be found at the end of this section.

#### Lord Joffe: 2003-6

Between 2003 and 2006, three attempts were made by Lord Joffe to introduce private members' bills that would have legalised assisted dying into the House of Lords. The most well-known of these attempts was the Assisted Dying for the Terminally Ill Bill, which reached second reading stage in the House of Lords in 2004 before being considered by a House of Lords Select Committee which published its findings in April 2005.<sup>404</sup> The Bill was prevented from progressing any further by the dissolution of Parliament pending the 2005 General Election. Lord Joffe reintroduced a modified version of his Bill into the House of Lords later that year. It was rejected by 148 votes to 100 at the conclusion of its second reading debate in May 2006.<sup>405</sup>

**Lord Falconer: 2014-15**

In 2010, the Commission on Assisted Dying (COAD), chaired by Lord Falconer, was established to “consider whether the current legal and policy approach to assisted dying in England and Wales is fit for purpose” and “investigate the circumstances under which it should be possible for people to be assisted to die in the UK.”<sup>406</sup> The Commission was hosted by the think tank Demos and funded by two private individuals, with the campaigning organisation Dignity in Dying brokering the relationship between the two.<sup>407</sup> The Commission published its final report in January 2012 and included proposals for the legalisation of assisted dying in the UK in which doctors would have a prominent role.<sup>408</sup>

In June 2014, Lord Falconer introduced the Assisted Dying Bill (often referred to as the Falconer Bill) into the House of Lords as a private member’s bill. This Bill was closely modelled on COAD’s findings, and would have permitted competent, terminally ill adults with a clear and settled intention to end their life, to receive physician assistance to do so. Two doctors would have to have been satisfied that the person was terminally ill and reasonably expected to die within six months; had capacity (construed in accordance with the Mental Capacity Act 2005); and had a clear and settled intention to end their life, which had been reached voluntarily, on an informed basis.

The Bill passed its second reading in the House of Lords in July 2014 after a debate with 126 peers speaking.<sup>409</sup> Line by line examination of the Bill in a committee of the whole House began in November 2014.<sup>410</sup> Over 170 amendments were tabled, and peers approved clause one amendments by a show of voices, which would introduce judicial oversight for all assisted dying decisions. The amendments, introduced by Lord Pannick, would require a judge of the High Court (Family Division) to confirm the two doctors’ recommendation on eligibility and to be satisfied that the patient’s wish was genuine and not coerced.<sup>411</sup>

Committee Stage continued in January 2015, where votes were taken on two amendments. The first was an amendment by Baroness O’Neill to refer to “assistance with suicide” rather than “assisted dying.” This was defeated by 180 votes to 107. The second was moved by Lord Carlile of Berriew and would have required at least one of the doctors assessing the individual to have known the patient for at least six months, with one having had responsibility for diagnosing and treating the illness. This was defeated by 119 votes to 61.<sup>412</sup>

The Bill fell when Parliament prorogued for the General Election on 30 March 2015.

**Rob Marris MP: 2015**

In June 2015, Labour MP Rob Marris, who topped the ballot for private members’ bills, introduced the Assisted Dying (No. 2) Bill into the House of Commons (“the Marris Bill”). The Marris Bill was nearly identical to the amended Falconer Bill, including the involvement of the High Court (Family Division). It also included a requirement that the court consider the application within 14 days.

The Marris Bill received its second reading in the House of Commons on 11 September 2015, where it was overwhelmingly rejected by 330 votes to 118.<sup>413</sup>

### *Main provisions of the Assisted Dying (No. 2) Bill*<sup>414</sup>

- **Patients** could make an application to the High Court (Family Division) for assistance in ending their life if they are aged 18 or over; have a terminal illness and are reasonably expected to die within six months; have a clear and settled intention to end their life; and have the capacity to make that decision. They must also have been resident in England or Wales for at least one year.
- The **judge** of the High Court (Family Division) would be required to rule on all requests within 14 days.
- An application could only be made to the court if the **request** was made in writing; signed by a witness (who could not be a relative or involved in the patient's care); and **countersigned** by two doctors who have examined the patient independently of one another. The "attending doctor" would usually be the person's GP or specialist consultant. The second doctor would be an "independent doctor" from a different practice or clinical team.
- Those two **doctors** must be satisfied that the patient is terminally ill; has the capacity (construed in accordance with the Mental Capacity Act 2005) to make the decision to end his or her own life; and has a clear and settled intention to do so, which has been reached voluntarily, on an informed basis and without coercion or duress. Both doctors must be satisfied that the patient has been informed of all their options, including palliative and hospice care available.
- If there are any doubts as to the capacity of the person requesting assistance, the doctor must refer that person for assessment to an "appropriate specialist".
- The attending doctor or another doctor or nurse authorised by the attending doctor ("**the assisting health professional**") would deliver the medication at the patient's request (after a cooling off period of fourteen days); prepare the prescribed medication for self-administration or prepare a medical device that would enable the individual to self-administer the medication; and stay with the person until the time of death. The final act must be performed by the patient him or herself.
- The Bill contained provisions which would enable the Secretary of State to determine how assisted deaths should be recorded and monitored.

As in the House of Lords debate on the Falconer Bill, the debate was characterised by MPs on both sides sharing their personal experiences of death and dying.<sup>415</sup> A large number of those who opposed the Bill did so on the grounds that it had the potential to go beyond its limits and to pressurise the elderly and other vulnerable people, particularly those without family support, to consider precipitating the end of their lives. Several MPs with medical experience spoke against the Bill, arguing that it had the potential to alter the doctor-patient relationship, and the "privileged" role that doctors currently play at the end of life. There were a number of calls – from both sides of the debate - to increase funding and improve access to and provision of palliative care.

MPs in favour argued that the Bill would maximise personal autonomy. Others argued that "everyone deserves a good death", and that assisting those who wish to die to do so is "compassionate" and "humane". Former DPP Keir Starmer QC, now MP for Holborn and St Pancras, argued that passing legislation would remedy two "limitations" he saw in the current legal status: firstly, that those seeking assistance to end their life could not access help from professionals; and secondly, that it only provided for an "after-the-event" investigation.

#### *Court involvement*

As explored in Chapter 4, doctors play a prominent role in assisted dying processes in all countries where the practice is permitted. In the Netherlands, Belgium, Luxembourg and all three US states (Oregon, Washington and Vermont) doctors are required to confirm that the individual seeking assistance meets the eligibility criteria; that the request has been made voluntarily; and then (depending on the law) to either administer or dispense the lethal substance. Even in Switzerland, where there is no specific requirement for medical involvement, the law has developed so that doctors (being the only profession who can dispense or prescribe barbiturates) are essentially gate keepers to assisted suicide.

Nowhere in the world is there a system of assisted dying which mandates the involvements of courts and the judiciary, although in April 2015, Colombia's Ministry of Health issued guidelines on euthanasia which would require all requests to be presented to a specialist committee, made up of medical experts, mental health professionals and lawyers.<sup>416</sup>

The issue of whether doctors should be involved in assisted dying processes has been seen as axiomatic in countries where it is legal. The main rationale is that doctors are equipped with all the necessary skills required to judge eligibility for assisted dying: assessment to confirm diagnosis and prognosis; assessment of the motivation behind a request; assessment of capacity and voluntariness; and exploration of an individual's understanding of and reaction to their health condition.<sup>417</sup>

All legislative proposals discussed in the UK have focussed on a medical model where doctors would be responsible for determining whether an individual meets the eligibility requirements. The Falconer and Marris Bills were the first to propose involvement of the courts to approve doctors' decisions: many peers saw this as adding an additional safeguard for both doctors and patients. Depending on the approach adopted, it could also remove or reduce the level of medical involvement. Additionally, judges currently play a role in some medical cases involving decisions at the end of life (such as the withdrawal of life-prolonging treatment), often where urgent decisions are required, and so have experience in adjudicating on these sorts of issues.

A number of peers, however, raised concerns about court involvement at committee stage of the Falconer Bill.<sup>418</sup> Particular concerns expressed were that such a legal process might be time-consuming and costly, and it was questioned how many very seriously ill individuals would have the resources and wherewithal to go through such a process. There were also concerns about how much of an additional safeguard this would be, given that judges would be asked to approve decisions already made by the doctors involved.

No legislative proposals have been considered which would remove doctors from decision making responsibility in any process of assisted dying completely. Under the most recent proposals for court involvement doctors would continue to play a key role in diagnosis, prognosis and the assessment of mental capacity, and in providing lethal drugs to the patient.

## 5. Scotland

### **Jeremy Purvis MSP: 2004**

In 2004 Liberal Democrat MSP Jeremy Purvis publicised a bill to legalise assisted dying, closely modelled on the Oregon Death with Dignity Act. At the consultation stage, the Bill seemed to have public support (56 per cent of respondents were in favour, and 33 per cent were against), but it failed to get the required number of supporting signatures from MSPs to be introduced into the Scottish Parliament.<sup>419</sup>

### **Margo MacDonald MSP (Patrick Harvie MSP): 2009-15**

In 2009 Scottish National Party MSP Margo MacDonald consulted on a proposed bill, the End of Life Assistance (Scotland) Bill, which proposed that doctors helping patients to end their lives should not be guilty of a crime, as long as certain criteria were fulfilled. In 2010 this Bill was defeated by 85 votes to 16 (with two abstentions) at the stage one debate.<sup>420</sup>

Margo MacDonald introduced her second bill on assisted dying, the Assisted Suicide (Scotland) Bill into the Scottish Parliament in November 2013. Following her death in April 2014, the Bill was taken forward by Green MSP Patrick Harvie.

### **Main provisions of the Assisted Suicide (Scotland) Bill**<sup>421</sup>

- **Patients** must be aged 16 or over; have an illness that is terminal or life shortening, or a condition that is progressive and either terminal or life-shortening; see no prospect of improvement in their quality of life; and after reflection, conclude that their quality of life is unacceptable. They must be registered with a medical practice in Scotland.
- They must have the **mental capacity** to make such a decision in line with the Adults with Incapacity (Scotland) Act 2000, and not be suffering from any mental disorder (within the meaning of s.328 of the Mental Health (Care and Treatment) (Scotland) Act 2003) which might affect the making of the request.
- The **request** must be made as an initial preliminary declaration that assisted suicide is an option the individual is willing to consider; made as a first formal request in writing at least seven days after the making of the preliminary request; and made as a second formal request in writing at least fourteen days after the making of the first. The requests must be made in the presence of a witness and endorsed by two medical practitioners.
- Two **doctors** must confirm that the person making the request has capacity; that the person has an illness that is either terminal or life-shortening, or a condition that is progressive and either terminal or life-shortening; and that the person's conclusion that their quality of life is unacceptable is not inconsistent with the facts known to the practitioner.
- A **licensed facilitator** (a new role created by the Bill) must provide, before, during and after the act of suicide, such practical assistance as requested by the individual; provide them with comfort and reassurance; and be with the individual at the time of death.
- The Bill's accompanying notes anticipated that the Scottish Government would appoint a body to be the authority for licensing and regulation.

The Health and Sport Committee was the primary committee for consideration of the Bill, and after taking oral and written evidence, published its report in April 2015. It concluded that the Bill contained significant flaws, which presented major challenges as to whether it could progress. Whilst the majority of the Committee did not support the general principles of the Bill, in light of the fact that the issue of assisted suicide is a matter of conscience, the Committee chose to make no formal recommendation to Parliament.<sup>422</sup>

The Scottish Parliament debated the Bill in May 2015, where it was rejected by 82 votes to 36, with no abstentions.<sup>423</sup> There will be no more opportunities for a bill to return before the next Scottish Parliament election in 2016.

### **Part Three: Doctors' views on assisted dying**

Doctors have an important voice in debates around any legislation on assisted dying, because if legalised, doctors are likely to be involved in the process to some degree: for example, counselling patients on available options, prescribing lethal substances, assessing capacity or referring patients to specialist euthanasia services. Some commentators have also noted that majority medical support, or at least neutrality, was a key enabling factor in the acceptance of legislation in the Netherlands, Belgium and Oregon.<sup>424</sup>

This section looks at the available qualitative and quantitative research into UK doctors' views on assisted dying, concentrating primarily on academic studies on the issue, and summarises the current policies of the main representative organisations of doctors, to the extent these are known. The aim here is to provide a general overview of the research in this area, as opposed to a critical appraisal of the relative quality of different studies. Some of data are based on surveys, and there are caveats which apply to these. Care needs to be taken in drawing conclusions or extrapolating findings more broadly from general surveys and polls on such a complex and emotive issue as assisted dying.



## 6. Research into the views of doctors on assisted dying

There have been numerous large-scale academic studies in recent years which have explored the attitudes of UK doctors towards assisted dying, both in terms of their support for possible changes to legislation and also the reasoning behind their viewpoints. Research has focussed on doctor populations either by stage in career or by specific specialties, including geriatricians, intensivists, GPs and psychiatrists.

The most recent systematic review of the research looked at 15 studies published between 1990 and 2010 to ascertain the attitudes of UK doctors towards euthanasia and physician-assisted suicide.<sup>425</sup> It incorporated and reported findings on both quantitative and qualitative data.

### – *Support for euthanasia and physician-assisted suicide*

The study authors stated that although there was a need to be cautious about comparisons across studies – differences in question phrasing being acknowledged as an accepted limitation, albeit one difficult to quantify – they argued that it could be inferred from the evidence that doctors did not support changes in legislation for either active voluntary euthanasia or physician-assisted suicide.

With respect to active voluntary euthanasia, 11 out of the 15 studies included in the review looked at the issue. In all but one of the surveys (which was published in 1994) the majority of doctors were opposed. Attitudes to physician-assisted suicide were investigated by 10 different studies with majority opposition reported in eight.

### – *Willingness to participate in assisted dying*

The study also looked at the evidence for the proportions of doctors who would be willing to perform either active voluntary euthanasia or assist in a suicide. Unsurprisingly, given the majority opposition to the legalisation of either form of assisted dying, only a minority of doctors would be willing to do so, although on average across the studies there were slightly more doctors willing to be involved in physician-assisted suicide (mean 24.9 per cent across eight studies) than active voluntary euthanasia (mean 22.7 per cent across six studies). Individual studies also indicated that amongst the doctors who agreed with the legalisation of assisted dying, some would not be prepared to be involved directly themselves.<sup>426,427</sup>

### – *Underpinning themes to attitudes of UK doctors*

Qualitative data was collected from six out of the 15 studies featured in the systematic review. From these the authors were able to identify a number of significant themes reported in two or more studies. (Other themes and significant findings are highlighted in the following section). Ordered from most to least prevalent, these common themes were as follows:

- Palliative care is an important provision and should be readily accessible.
- Appropriate safeguards must be established if either active voluntary euthanasia or physician-assisted suicide is introduced, for example, clearly defined referral pathways, clear legislation, audit and review, and appropriate training.
- Although a number of studies highlight concerns about combining being a doctor and assisted dying, evidence from the review suggested that opinion was divided on whether or not providing active voluntary euthanasia or physician-assisted suicide was compatible with the role of the doctor.
- There is concern that introducing active voluntary euthanasia or physician-assisted suicide could result in harm, in particular to patients and society. Examples include the social coercion of the vulnerable, the balance of short-term gain for some individuals against potential long term disservice to society, and that it may undermine the social process of grieving or dying.
- All doctors want to protect patients' rights.

## 7. Other relevant findings

### Terminal illness and non-terminal conditions

Seale surveyed 3,733 doctors on whether, for patients who suffer “an incurable and painful illness”, the law should be changed to allow doctors to end a patient’s life (active voluntary euthanasia). Less than 20 per cent (17.7%) believed this definitely should be allowed; 28.1 per cent believed it probably should.<sup>428</sup> Support for physician-assisted suicide for the same groups of patients was slightly higher at 21.7 per cent. These figures are low when compared to the view of the general public. As explored below, support amongst the public for assisted dying for individuals who do not have a terminal illness but who nevertheless are suffering from a painful and incurable condition and wish to die is consistently weaker than in circumstances involving terminal illness – but the level of support is slightly higher amongst the public than it is in doctors.

### Factors which influence views on assisted dying

Similar to the research evidence on the views of the UK public (see below), the most significant factor across all studies which influences attitudes to assisted dying is religiosity. Doctors who report being religious or having faith was a statistically significant factor in a number of studies which negatively influences the opinion of doctors towards assisted dying.<sup>429</sup>

McCormack *et al* found there to be conflicting results as to whether increased exposure to dying patients or working in palliative medicine was related to opposition to assisted dying, with one study<sup>430</sup> showing there to be a statistically significant association between working with the dying and opposition to physician-assisted suicide, while another highlighted that more experience was not independently associated with opposition to assisted dying once specialty and religiosity were controlled for.<sup>431</sup>

In research published in 2008, Kitching *et al* sought the views on physician-assisted suicide of 147 medical professionals who were at different stages of their medical career via a postal questionnaire.<sup>432</sup> The mean responses from the study suggested that professionals thought they had a better awareness of the legal position with progressive experience, however, there was little evidence to support a hypothesis that the opinions of doctors changed as they progressed through their career, suggesting that viewpoints on the issue were based more on personal beliefs rather than experience.

### Practical issues in the event of assisted dying being legalised

As discussed above, a common viewpoint amongst doctors is the need for safeguards to prevent abuse should assisted suicide be legalised, although for some doctors no amount of safeguards would be able to protect vulnerable individuals. The need for an opt-out clause for doctors is cited in a number of studies,<sup>433</sup> while various respondents advocate either specialisation in assisted dying (not necessarily involving doctors)<sup>434</sup> or a special service for the purposes of facilitating assisted dying<sup>435</sup> in the event of legalisation.

A number of studies have touched on issues associated with mental health and mental capacity. A national survey of psychiatrists, published in 1998, showed that the majority of respondents (64%) strongly agreed that there should be a psychiatric assessment in all cases although only 35 per cent agreed that they would be willing to assess psychological suitability.<sup>436</sup> Kitching *et al* also found there to be agreement amongst respondents that a mental capacity assessment by a psychiatrist should be part of any legalised process for physician-assisted dying.<sup>437</sup>

The questionnaire in Kitching *et al* also sought the views of doctors on other practical issues that might arise should physician-assisted suicide be legalised in the UK:

#### – *Involvement of coroner*

A large proportion of respondents felt that the involvement of a coroner could promote public confidence in the practice of assisted dying, but there was no consensus on whether this would deter doctors from taking part. In the discussion of the results the authors cited evidence from the Netherlands which showed that doctors were more reluctant to report cases of euthanasia where the medical examiner and public prosecutor were involved in the review process.

– *Multidisciplinary approach*

There was a very strong consensus that if physician-assisted suicide was legalised, more than one doctor should be involved, with some support for a multidisciplinary approach involving the patient's hospital specialist, GP, and palliative care specialist.

– *Limits on the number of patients and counselling*

There were equal numbers of respondents who agreed and disagreed with the proposal that there should be a limit on the number of patients a doctor could assist to die, but there was more general agreement that there should be mandatory counselling for all doctors involved in the process.

– *Dealing with family members*

There was strong disagreement about whether all family members should be in agreement before an assisted suicide was to take place.

– *Setting of physician-assisted dying*

Many doctors surveyed agreed that patients should be able to choose the setting where physician-assisted suicide would take place and that there should be a responsibility on health authorities to provide such a setting if it was legalised.

– *Participation in physician-assisted suicide for a family member*

The questionnaire also asked doctors in the sample whether they would be prepared to help family members if the drug was prescribed by another medical professional. Significant numbers declined to answer the question but of those that did, 32 per cent strongly disagreed.

## 8. Surveys and polls of doctors' views

In 2014 a survey by Medix canvassed the views of 600 UK doctors on a range of questions associated with physician-assisted suicide and euthanasia.<sup>438</sup> On the central question of whether there should be a change in the law to permit either form of assisted dying, the results are consistent with the studies outlined above with the majority stating that there should not be a change in the law for physician-assisted suicide (58%) or euthanasia (54%), with 29 per cent stating that they were in favour of either option. When asked whether they would take part if physician-assisted suicide was legal, 56 per cent said no, 19 per cent said yes, and 24 per cent were either unsure or preferred not to say. For euthanasia, 58 per cent said they would not take part, 18 per cent said they would, while 23 per cent were unsure or preferred not to say. The survey also explored other issues and some of findings are given below:

- 29 per cent had been asked by a patient to assist in their suicide or euthanasia compared to 63 per cent who had not;
- 53 per cent believed that the NHS should provide a service if either was legalised;
- 37 per cent of participants thought that there were circumstances where some UK health professionals assisted their patients to die, 22 per cent thought not and 37 per cent were unsure;
- 48 per cent of participants either agreed or strongly agreed that "assisted dying or physician-assisted suicide for the terminally ill empowers patients who wish to take more control of their end of life care" whereas 35 per cent disagreed or strongly disagreed and 18 per cent neither agreed or disagreed; and
- doctors were seen as most important in the overall decision to legalise physician-assisted suicide, followed by patient groups, the public, politicians and, lastly, religious groups.

In 2015, a poll of 1,000 GPs by medeConnect (a division of doctors.net.uk) asked for views on the proposed Marris Bill then under consideration in the House of Commons.<sup>439</sup> Thirty-four per cent (34%) indicated support for it, 20 per cent were neutral on the issue and 41 per cent indicated they were opposed. When asked what, if anything, they would be prepared to undertake if assisted dying became legal, 49 per cent stated they would not want to be involved at all; 39 per cent indicated they would conduct an assessment of the patient's request; 21 per cent would prescribe the life-ending medication if a court had declared the patient eligible; and 11 per cent would deliver the medication to the patient's home and be present when they took it.

An earlier medeConnect poll of 878 GPs in England and Wales in 2014 also found that 40 per cent of GPs would want the choice of an assisted death if they were terminally ill, while 25 per cent were unsure, and 32 per cent would not want the choice.<sup>440</sup>

## 9. Policies of doctors' organisations

The level of majority opposition of doctors which is reported in the research literature over at least the past two decades has been reflected in the policies of doctors' representative bodies. With the exception of the Royal College of Psychiatrists, which is neutral, all organisations with policy on the issue are opposed to all forms of assisted dying, while also acknowledging that there are a range of different views within their respective memberships. There are calls, however, for doctors' organisations to adopt a neutral stance. The 2015 medeConnect poll highlighted that 56 per cent of the GPs sampled agreed that medical bodies should adopt a position of neutrality,<sup>441</sup> down from 61 per cent in 2014.<sup>442</sup>

### The British Medical Association (BMA)

The BMA has consistently opposed all forms of assisted dying, with the exception of 2005 when the policy changed to neutral before subsequently reverting back to opposition the following year. The Association's policy is made at its Annual Representative Meeting (ARM) and current policy dates back to 2006 and states that the BMA:

- Believes that the ongoing improvement in palliative care allows patients to die with dignity.
- Insists that physician-assisted suicide should not be made legal in the UK.
- Insists that voluntary euthanasia should not be made legal in the UK.
- Insists that non-voluntary euthanasia should not be made legal in the UK.
- Insists that if euthanasia were legalised there should be a clear demarcation between those doctors who would be involved in it and those who would not.<sup>443</sup>

The most recent debate was at the 2012 ARM, when members rejected a motion calling for organisational neutrality.

### Royal College of General Practitioners (RCGP)

In February 2014, the RCGP announced the results of a consultation of its 50,000 members which resulted in continued opposition to legislative change to allow assisted dying.<sup>444</sup> The consultation process involved 1,713 respondents through local debates, meetings and surveys; individual response forms on the RCGP website; and groups and committees within the college.

Seventy-seven per cent (77%) of the 234 members who submitted individual responses expressed the view that the college should maintain its position of opposition, with 18 per cent stating the RCGP should be neutral on the issue, and 5 per cent supporting the view that the RCGP should support a change in the law.<sup>445</sup> Analysis by the RCGP of the views that were submitted via other routes – devolved Councils, faculties, groups and committees (engaging 1,479 people) – also indicated that the majority favoured opposition.

Among the reasons cited by participants in the consultation for opposition were the detrimental impact on the doctor-patient relationship; risks to vulnerable groups; the possibility of coercion; a shift of focus away from investment in palliative care and treatments for terminal illness; and the risk of a "slippery slope" to allowing assisted dying for other groups, such as adults without the capacity to consent. Those who wanted the RCGP to be neutral felt it would make patients feel more at ease about discussing the issue with their doctors; and that Parliament and the voting public should decide, with the RCGP providing objective advice and guidance. Those who wanted the RCGP to support assisted dying cited that it was wrong to deny patients with capacity the right to end their lives in a way of their choosing; and that good safeguards could be put in place.

**Royal College of Physicians (RCP)**

The RCP has polled its 30,000 members twice on the issue of assisted dying. Most recently, in November 2014, members were asked whether they supported a change in the law to allow physician-assisted suicide for the terminally ill: 57.5 per cent of 6,710 respondents were opposed, 32.3 per cent believed that the law should be changed and 10.2 per cent agreed with a change where doctors are not involved.<sup>446</sup> With respect to the College's position on "assisted dying", 24.6 per cent believed it should support, 44.4 per cent voted for opposition and 31 per cent for a neutral or no stance. On the basis of these figures the College reaffirmed its position opposing assisted suicide.

The previous RCP survey of members in 2006 asked members whether they agreed with the following statement: "(We) believe that with improvements in palliative care, good clinical care can be provided within existing legislation, and that patients can die with dignity. A change in legislation is not needed." Over seventy per cent (73.2%) agreed and 26 per cent said they did not agree. In 2014, the RCP asked its members this question again, so as to allow comparison between the two dates, and found that while the majority still agreed with the statement, the level of support for the statement had fallen to 62.5 per cent. Just over 37 per cent (37.5%) did not agree with the statement.

Both the 2006 and 2014 surveys asked members whether they would consider participating in assisted suicide should it be legalised. In 2014, 58.4 per cent opposed participation, while 20.1 per cent were neutral and 21.4 per cent were in favour. Roughly similar results were found in the 2006 survey.

**The Association for Palliative Medicine of Great Britain and Ireland (APM)**

In January 2015, the Association for Palliative Medicine (APM) surveyed its members, doctors working in palliative medicine across all grades and levels of experience, to ascertain their views on assisted suicide.<sup>447</sup> The APM conducted the survey when Lord Falconer's Assisted Dying Bill and the Assisted Suicide (Scotland) Bill were being debated in Westminster and the Scottish Parliament respectively. It was sent electronically to all 996 members and 387 (39%) responded.

The survey focussed on Lord Falconer's proposals and sought views on whether it should become law. In response to the question, "Do you think that the law in the UK should be amended to allow Assisted Suicide as proposed in Lord Falconer's Bill?" 81.46 per cent of respondents said no, 11.78 per cent said yes and 6.58 per cent said they don't know. The survey then asked whether, if the law in the UK was changed, it should be "within routine medical practice or should its assessment, approval and implementation be entirely outside the sphere of medicine, for instance in the family court?" 82.04 per cent thought that it should be outside medicine, compared with 4.97 per cent who thought it should be part of routine medicine and 12.98 per cent who didn't know.

The survey also asked what APM members would be prepared to do, if assisted suicide became legal, across three different scenarios. The results are given in table 5 below.

**Table 5: APM survey – level of involvement if Assisted Dying Bill became law<sup>448</sup>**

If assisted suicide became legal in the UK in the current bill you would be able to limit your involvement to the level your conscience permitted. So would you personally be prepared to:	Yes	No	Don't know
Participate fully in its implementation by assessing and deciding suitability, recommending to the court and prescribing lethal medication?	4.43%	88.64%	6.93%
Assist the court by preparing judgements to the court to support the court's decision (e.g. assessment of capacity, fixed will, and degree of coercion)?	21.70%	62.36%	15.93%
Provide a court with factual information alone (e.g. diagnosis, extent of disease, involvement of palliative care services etc.)?	70.91%	15.79%	13.30%

Finally, the survey asked respondents about the impact legalising assisted suicide, either Lord Falconer's bill or one similar, would have on the delivery of palliative care, including that provided by hospices. Seventy-three per cent (73%) thought it would have either an adverse or very adverse impact, 22 per cent thought it would have a neutral impact, 4 per cent thought it would have a positive effect, while 1 per cent thought it would have a very positive effect.

#### Part Four: Polls and surveys of public views on assisted dying

Most of the available information on public attitudes towards assisted dying comes from surveys or polls of public opinion which consistently show strong public support for a change in the law. This is a complex and emotive issue which does not lend itself easily to simple yes or no survey-type questions and so it is unfortunate that there remains a paucity of in-depth qualitative research on public and patients' views on assisted dying specifically in a UK context.

Nevertheless, the views of the UK public form an important component of debate on this topic, and surveys and polls provide a broad indication of that. As noted in the above section on the views of doctors, there are some caveats about the limitations of the results of these types of surveys in interpreting the findings. In 2005, the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill warned that the surveys of the public that had been carried out "tend to produce findings which at best may be considered one-dimensional. Simple, direct questions placed without a proper explanatory context and with limited options for reply can sometimes produce results which in fact may be misleading".<sup>449</sup> Differences in the way a question and possible responses are phrased, whether options are provided, the terminology used, and how it is defined can all potentially affect survey results.<sup>450,451</sup>

With these caveats, the aim of this section is to provide a general overview of published research on public views regarding assisted dying, rather than to critically appraise the relevant quality of different studies. The section is therefore split into three parts. The first looks at the results from the British Social Attitudes (BSA) survey, which has canvassed opinion on assisted dying in some form on a number of occasions since the mid-eighties and most recently in 2010. The second section reports more recent polls of the public on assisted dying to provide a snapshot of current attitudes amongst the general public and specific population groups. Lastly the chapter looks at other research on public views on assisted dying, including the limited available qualitative research.

## 10. The British Social Attitudes Survey (BSA)

The issue of assisted dying has been raised in a number of different BSA surveys. The BSA is generally regarded as one of the most reliable surveys of public opinion as it uses a large and diverse sample and is repeated regularly. It is therefore considered to provide high quality and independent data which, for some, helps form an understanding of attitudes to assisted suicide and euthanasia within the UK over time.<sup>452</sup>

One question which has been asked of the public in all these surveys is whether the law should allow active voluntary euthanasia performed by a doctor for a patient with a “painful incurable disease” (see Table 6). The results suggest that there has been a small trend since 1989 towards support for a law allowing a doctor to end the life of a patient with painful, incurable disease.

**Table 6 – Attitudes to voluntary euthanasia in BSA surveys**

Should the law allow a doctor to end the life of a patient with painful incurable disease?	1984	1989	1994	2005	2010
Yes	75	79	82	80	82
No	24	20	15	18	n/a*
Base	1,562	1,274	1,000	1,786	2,250

\*figure not provided in report

The BSA has looked in detail at the issue of assisted dying twice, in 1996<sup>453</sup> and in 2007.<sup>454</sup> The more recent of these analyses, based on fieldwork conducted in 2005, had two main aims: to establish in what circumstances, if any, it would be acceptable to the public for someone to be helped to die (defined as “assisted dying”) and to consider the underlying attitudes which inform this viewpoint. The study analysed the levels of support across five different scenarios and assessed whether people thought assisted dying in three different forms should either “definitely” or “probably” be allowed for each – the results are provided in table 7 below.

**Table 7 – BSA 2005 – Levels of support for alternative forms of assisted dying<sup>455</sup>**

“Definitely” or “probably” should be allowed for a person...	Voluntary euthanasia by a doctor	Physician-assisted suicide	Voluntary euthanasia by a relative
...with an incurable and painful illness from which they will die – for example someone dying of cancer (Base: 2176)	80%	60%	44%
...with an incurable illness from which they will die, and who says their suffering is unbearable (Base: 1101)	74%	58%	n/a*
...with an incurable and painful illness from which they will not die (Base: 1101)	45%	40%	n/a*
...who is not in much pain, not in danger of death but becomes permanently and completely dependent on relatives for all their needs – for example, someone who cannot feed, wash or go to the toilet themselves (Base: 2176)	43%	n/a*	24%
...with an incurable and painful illness from which they will not die – for example, someone with severe arthritis (Base: 1075)	33%	32%	n/a*

\*Not asked

The results show that voluntary euthanasia administered by a doctor has the most support across all scenarios. Unlike many of the BSA surveys, in 2005 the sample was asked specifically about views on physician-assisted suicide. As the table above shows this also obtained greater than majority support in circumstances where the patient was dying. The results show that views on assisted dying can vary when considered for different circumstances. Assisted dying in terminal illness is seen as more acceptable than for other conditions for both voluntary euthanasia by a doctor and physician-assisted suicide. The least popular circumstances under which assisted dying is deemed acceptable is where it is administered by a relative. Explanations offered for this by the authors include fear of people being pressured; that doctors may be expected to take a more detached view of the situation; and that relatives may not have the expertise required to administer euthanasia. (It should be noted that the definition of “voluntary euthanasia by a relative” refers specifically to a relative administering a substance to help someone to die and not “assisted suicide” where a relative assists the suicide of a person, which has been the focus of the more recent surveys discussed below).

In looking at the arguments which underpin attitudes to opposition to assisted dying, the BSA report on the 2005 data found that religion played an important part in people’s viewpoints and, in particular, how often someone attends a religious service. As the authors state, “religion is a key mechanism through which opposition to assisted dying is both generated and maintained”.<sup>456</sup> Support for assisted dying was correlated with a belief regarding the importance of autonomy.

The 2010 BSA survey report<sup>457</sup> also focussed, in part, on religious faith, looking at the differences in attitudes to contemporary issues in those who were “religious” (531 respondents), “fuzzy faithful” (810) or “unreligious” (638). As Table 7 above shows, on the issue of assisted dying, and specifically on whether “a doctor should probably or definitely be allowed to end the life of a patient with a painful incurable disease”, 82 per cent of all respondents to the question believed that it either “definitely” or “probably” should be allowed. When divided into the religiosity groupings given above, 71 per cent of religious respondents believed that it should be allowed compared to 85 per cent of fuzzy faithful and 92 per cent of unreligious respondents.<sup>458</sup>

Using BSA data for 1983-4 Gill found that among Anglican weekly churchgoers a majority (66%) supported euthanasia for the terminally ill (compared with 76% in the general population), but that among Catholic weekly churchgoers only a minority (39%) did so.<sup>459</sup> Using BSA data for 2008 he found that among Anglican weekly churchgoers a majority (61%) supported euthanasia for a person who ‘has a painful incurable disease’ and a majority (57%) of Catholic weekly churchgoers. Support in 2008 was weakest (34%) among weekly attenders from other faiths.<sup>460</sup>

## 11. Recent public polls and surveys

There have been a significant number of polls of the public and specific population groups on assisted dying in recent years. Given the focus of proposed legislation in Scotland and England, they have concentrated mainly on assisted suicide rather than other forms of assisted dying. Although many polls have sought to broadly establish opposition or support, some have also tried to “dig deeper” into the position of respondents by looking at the levels of support for the different arguments on either side of the debate or by analysing the attitudes that underlie the public’s viewpoints.

The surveys have been commissioned by a range of organisations, including campaigners for a change in the law, disability groups, faith groups and the media. This section focuses on surveys which have been conducted in the last five years so as to provide a snapshot of current attitudes to the prevailing policy context.



### Terminal illness and non-terminal illness

A number of recent public surveys draw the distinction between a change in the law to allow assisted suicide in circumstances where someone has a terminal illness and where they have “a painful incurable illness from which they will not die”. In line with the results from the BSA surveys, there remains strong support for creating a legal provision for people with terminal illness to be assisted in dying, but support is weaker for painful and incurable illnesses which are not terminal.

In 2015, *The Economist* commissioned an international survey on assisted dying in 15 different countries.<sup>461</sup> The poll was conducted by Ipsos Mori and involved 2,162 UK adults aged between 16 and 75. The sample were asked:

“Do you think it should be legal or not for a doctor to assist a patient aged 18 or over in ending their life, if that is the patient’s wish, provided that the patient is terminally ill (where it is believed that they have six months or less to live), of sound mind and expresses a clear desire to end their life?”

Seventy per cent (70%) of the respondents believed that it should be legal, 13 per cent believed it should not, 14 per cent did not know and 3 per cent preferred not to say. For patients aged under 18, where there is consent from a parent or guardian alongside a desire from the patient to end their life, support drops to 38 per cent for patients aged 15-17, 25 per cent for patients aged 11-14 and 23 per cent for patients aged 10 and under.

The sample was also asked whether it should be legal for a doctor to be able to assist someone aged 18 or over to die who was not terminally ill but was “physically suffering in a way that they find unbearable and which cannot be cured or improved with existing medical science”. Support for legalisation in these circumstances is less than for terminal illness at 58 per cent, with 18 per cent disagreeing and 20 per cent stating that they did not know. The survey also asked whether the law should be changed for those with unbearable mental suffering. Again the support decreases further to 37 per cent, with 32 per cent of those surveyed against the proposal.

It is not clear what “assistance” refers to in these instances as it is not specified. There are separate questions in the survey which ask the views of the sample on whether it should be legal for a doctor to assist a patient over 18 by prescribing life-ending medication for the patient to take themselves or administering life-ending medication, although the type of illness is not specified. Support for legalisation is the same at 58 per cent for both options. The remaining breakdown is also similar. With respect to prescribing life-ending medication, 23 per cent did not think it should be legal and 16 per cent did not know. This is compared with 21 per cent and 18 per cent respectively for doctors administering life-ending medication.

Of the 2,095 respondents to a YouGov survey for the *Sunday Times* in 2014,<sup>462</sup> 69 per cent believed that the law should be changed, 13 per cent disagreed and 18 per cent stated that they were not sure. However, support for legal change in cases where an individual did not have a terminal illness but suffered from a painful incurable disease dropped to 42 per cent, with 30 per cent stating that the law should not be changed and 28 per cent who did not know. The survey found there to be little variation in feelings about the issue in general by age, gender or other demographics. These figures are similar to an earlier survey commissioned by the *Sunday Times* in 2012.<sup>463</sup>

### Family members assisting suicide

Two surveys commissioned by the BBC – one for Panorama in 2010<sup>464</sup> and another in 2011 for Newsnight<sup>465</sup> – surveyed the public specifically about circumstances where assistance was provided by a family member or by a doctor. Again, in both surveys support was weaker in cases where an individual did not have a terminal illness, with a relatively even split between those that agreed and disagreed for both family member and physician-assisted suicide. The 2010 survey found equal support for both family members and medical professionals being allowed to assist an individual who has a terminal illness in committing suicide who would otherwise be physically incapable of doing so (73% and 74%). In the 2011 survey the level of support for doctors being involved remained roughly the same at

75 per cent although support for the involvement of family members dropped slightly to 69 per cent.

A YouGov survey<sup>466</sup> of 4,437 adults in Great Britain, commissioned for the Westminster Faith Debates in 2013 by the University of Lancaster, also concentrated on changing the law to allow friends or relatives to assist them in committing suicide:

“Do you think British law should be kept as it is, or should it be changed so that people with incurable diseases have the right to ask close friends or relatives to help them commit suicide, without those friends or relatives risking prosecution?”

It is worth noting that the question only refers to “people with incurable diseases” rather than specifying whether or not it was a terminal illness. In response, 70 per cent of the adults surveyed believed the law should be changed in these circumstances and 16 per cent believed it should be kept as it is. The survey also sought to examine the reasons behind either opposition or support. It presented both those who believed the law should be changed and those who did not with different arguments and asked which best described their view-points. The results (see Table 8 below) suggest, in line with the results from the BSA survey report in 2007, that autonomy-based arguments are the most prevalent amongst those who believe the law should be changed. Concerns about vulnerable people feeling pressured to die were supported by most who opposed legislative change.

**Table 8 – University of Lancaster – Westminster faith debates – YouGov Survey, Jan 2013**

Arguments which describe viewpoint – retaining current law	%
Vulnerable people could be, or feel, pressured to die	59
It places too much of a burden on the person or people who help someone to die	55
You can never build in enough safeguards	48
Human life is sacred	48
Death should take its natural course	46
No-one can ever be certain that they really want to die, but the decision is irreversible	43
Other	3
Don't know	3
Arguments which describe viewpoint – change law	%
An individual has the right to choose when and how to die	82
Preferable to drawn out suffering	77
Those assisting suicide should not fear suffering	76
It is happening anyway and regulation would improve safety and delivery	51
National health and welfare systems can't provide decent end of life care	35
Other	1
Don't know	1

Most recently, a survey conducted in 2015 by Populus for Dignity in Dying<sup>467</sup> asked:

“If a terminally ill loved one was suffering unbearably and asked you to assist them in their dying, how likely, if at all, would you be to consider assisting them, even though this would currently be breaking the law?”

Of the 5,018 participants, 14 per cent said that they would “definitely” consider assisting them and 31 per cent would “probably” consider assisting them compared with 16 per cent who said they probably would not and 13 per cent who said they definitely would not. Twenty-seven per cent (27%) did not know.

### The Assisted Dying Bill

Recent surveys have focussed on specific provisions and safeguards which underpinned the recently debated Assisted Dying Bills. The exact questions posed change slightly across the different surveys over time, often as safeguards have changed, but there is sustained public support for the Bill across the surveys, consistent with more general surveys and the BSA findings. Most recently, in 2015, the Dignity in Dying/Populus survey<sup>468</sup> asked the following question:

“Currently it is illegal for a doctor to help someone with a terminal illness to end their life, even if the person considers their suffering unbearable and they are of sound mind. A proposed new law would allow terminally ill adults the option of assisted dying. This would mean being provided with life-ending medication, to take themselves, if two doctors thought they met all of the safeguards. They would need to be of sound mind, be terminally ill and have 6 months or less to live, and a High Court judge would have to be satisfied that they had made a voluntary, clear and settled decision to end their life, with time to consider all other options. Whether or not you would want the choice for yourself, do you support or oppose this proposal for assisted dying becoming law?”

The inclusion of the role of a judge reflects amendments to the Falconer Bill at committee stage in the Lords. In total, 82 per cent of respondents signalled they “strongly” or “somewhat” supported the proposal, 12 per cent “strongly” or “somewhat” opposed while 6 per cent did not know. The survey further asked what impact the role that doctors would play in the proposal – i.e. independently exploring the patient’s reasons, reviewing his or her care, consulting with other professionals and writing the prescription – would have on trust in doctors to always act in the best interests of patients. Fifty per cent (50%) stated that it would make no difference to the trust in doctors to always act in the best interests of the patient; whilst 13 per cent stated that it would significantly increase the trust and 25 per cent stated that it would somewhat increase trust in doctors. Four per cent (4%) and 8 per cent stated it would significantly reduce trust and somewhat reduce trust, respectively.

A YouGov survey<sup>469</sup> in October 2014, commissioned by Dignity in Dying, asked 1,727 adults in Great Britain the following question, based on the wording of the Bill at the time, and also looked closer at other arguments:

“Currently it is illegal for a doctor to help someone with a terminal illness to end their life. There will be a Bill in Parliament this year that, if passed, would allow terminally ill adults the option of assisted dying. This would mean being provided with life-ending medication to take themselves if two doctors thought they met all of the safeguards. They would need to be of sound mind, be terminally ill and have 6 months or less to live, and have made a clear and settled decision with time to consider all other options.

Whether or not you would want the choice for yourself, to what extent would you support or oppose this Assisted Dying Bill becoming law?”

Overall support for the Assisted Dying Bill on the basis of this question was 77 per cent. Of the remaining adults 13 per cent opposed the Bill and ten per cent did not know.

Respondents were then presented with a range of arguments both for a change in the law and against a change in the law and asked to indicate how convincing it found each argument (Tables 10 and 11).

**Table 9 – Dignity in Dying/YouGov poll, October 2014 – arguments against assisted dying**

Arguments	Very convincing	Fairly convincing	Fairly unconvincing	Very unconvincing	Don't know
Many surveys show the majority of doctors oppose a change in the law to permit assisted suicide, as does the British Medical Association, the Royal College of Physicians, the Royal College of General Practitioners, the British Geriatric Society and the Association for Palliative Medicine.	8%	28%	26%	12%	26%
All major disability rights advocacy groups in Britain oppose a change in the law to permit assisted suicide including Disability Rights UK, SCOPE, UK Disabled Person's Council and Not Dead Yet UK.	10%	26%	26%	13%	25%
The risk of people feeling pressurised into ending their life early so as not to be a financial or care burden on loved ones, as has happened in the US where more than six in ten of those requesting a lethal prescription in Washington State (where the law is similar to that proposed in the House of Lords debate) say that one of their reasons for doing so was not to be a burden on friends, family or caregivers.	15%	35%	19%	7%	24%
Concerns that end-of-life care would be likely to worsen under financial pressures because it costs on average £3,000 to £4,000 a week to provide in-patient hospice care, but just a one-off cost of £5 to pay for the drugs which would help them commit suicide.	16%	29%	19%	12%	25%
Changes in the law to allow assisted suicide and/or euthanasia in other countries like Belgium, the Netherlands and Switzerland have led to a steady annual increase in the number of cases and spread of the practice to involve people with chronic but not fatal diseases, disabled people, children and those with mental illnesses and dementia.	12%	29%	21%	10%	28%

**Table 10 – Dignity in Dying YouGov poll, October 2014 – arguments for assisted dying**

Arguments	Very convincing	Fairly convincing	Fairly unconvincing	Very unconvincing	Don't know
Thousands of doctors support a change in the law and polling this year found almost two thirds of doctors would support a safeguarded system for terminally ill patients, rather than the current system which prohibits a safeguarded practice.	22%	45%	10%	5%	19%
A poll of 1,000 disabled people found that 79% would support a change in the law to allow assisted dying for terminally ill adults.	25%	42%	10%	6%	16%
The lack of a safeguarded assisted dying law forces some dying people to take matters into their own hands. For example, those that can afford it can travel to Switzerland to die. Not only would a change in the law provide the choice to have an assisted death at home, but it would also provide better protection through upfront safeguards.	28%	39%	9%	4%	19%
The proposed law in England and Wales is more tightly defined than those in some other European countries; instead it is very similar to the assisted dying law in Oregon, USA, which has not changed in the 17 years since it was introduced. The proposed law would only be available to terminally ill adults with the mental capacity to make the decision. It would not apply to people with non-terminal diseases, disabled people, children or people with mental illnesses.	27%	37%	9%	5%	23%
Nearly all patients who have assistance to die in the US state of Oregon receive hospice care and support up until they die and many more dying patients take comfort from knowing the choice of assisted dying is there. End-of-life care improves in places where assisted dying is legal practice.	31%	37%	8%	4%	20%

Having been presented with these arguments, support amongst the public dropped to 69 per cent, with an increase in those that don't know (17%) but no increase in opposition. A similar survey was conducted earlier in 2014 by ComRes on behalf of Christian Action Research and Education (CARE).<sup>470</sup> Participants were first asked for their support in principle for the Assisted Dying Bill:

"A new Bill is due to be debated in the House of Lords which is designed to enable mentally competent adults in the UK who are terminally ill, and who have declared a clear and settled intention to end their own life, to be provided with assistance to commit suicide by self-administering lethal drugs. Two doctors would need to countersign their declaration and be satisfied that the person has a condition which cannot be reversed by treatment and is reasonably expected to die within 6 months. In principle would you agree or disagree with this proposal?"

Of the 2,055 adults polled, 73 per cent (1,059) agreed with the proposal and 12 per cent disagreed. This sample was then asked for their views on the same arguments against assisted dying as those listed above in Table 9, and asked whether or not they made them change their mind. In each case most respondents stated that they would not change their mind but a number of those who previously agreed responded to say they either would oppose or didn't know – see Table 11 below. Overall, at the end of the survey, 43 per cent supported assisted dying, 43 per cent opposed, and 14 per cent did not know.<sup>471</sup>

**Table 11 – ComRes on behalf of Christian Action Research and Education (CARE), July 2014**

Given your support for the proposal in principle, would each of the following arguments against allowing assisted suicide make you change your mind or not?	Would still support (%)	Would oppose (%)	Don't know (%)
The risk of people feeling pressurised into ending their life early so as not to be a financial or care burden on loved ones, as has happened in the US where more than six in ten of those requesting a lethal prescription in Washington State (where the law is similar to that proposed in the House of Lords debate) say that one of their reasons for doing so was not to be a burden on friends, family or caregivers.	47	28	25
Changes in the law to allow assisted suicide and/or euthanasia in other countries like Belgium, the Netherlands and Switzerland have led to a steady annual increase in the number of cases and spread of the practice to involve people with chronic but not fatal diseases, disabled people, children and those with mental illnesses and dementia.	58	21	21
Concerns that end-of-life care would be likely to worsen under financial pressures because it costs on average £3,000 to £4,000 a week to provide in-patient hospice care, but just a one-off cost of £5 to pay for the drugs which would help them commit suicide.	59	15	27
All major disability rights advocacy groups in Britain oppose a change in the law to permit assisted suicide including Disability Rights UK, SCOPE, UK Disabled Person's Council and Not Dead Yet UK.	63	12	25
Surveys consistently show the majority of doctors oppose a change in the law to permit assisted suicide, as does the British Medical Association, the Royal College of Physicians, the Royal College of General Practitioners, the British Geriatric Society and the Association for Palliative Medicine.	65	10	25

In 2014, a survey of 2,019 people by ComRes on behalf of Care Not Killing and Not Dead Yet, two anti-assisted dying groups, also looked at the attitudes to the Assisted Dying Bill in the House of Lords ahead of it being debated.<sup>472</sup> The participants were asked two questions then asked whether they agreed or disagreed with a set of statements. Unlike the surveys outlined above, no detailed information on the Bill was provided as part of the survey. The questions and statements covered a broad range of issues including many of those in the Dignity in Dying poll described above:

“Next week the House of Lords will be discussing changing the law on assisted suicide. The changes are opposed by most of the leading doctors’ groups and many disabled groups like Scope and Radar. Do you agree or disagree with these statements about this issue?”

Statements	Agree	Disagree	Don't know
If the law is changed then some vulnerable people like the elderly, disabled or terminally ill will inevitably feel pressured into ending their lives prematurely.	48%	30%	22%
People should have the right to end their lives whenever they choose and the state should help them by providing lethal drugs for this purpose.	54%	21%	26%
I agree with the author Martin Amis who thinks elderly people should be rewarded for ending their lives.	10%	64%	26%
Weakening the protections of the current legislation will lead to more people dying prematurely.	35%	31%	35%
If the law is changed so that people are able to be given lethal drugs to end their life prematurely, it will be impossible to make the system completely safe from abuse by unscrupulous relatives or others who could influence the process.	58%	18%	24%

“A House of Lords report found ‘no safe system’ anywhere in the world, while those opposing a change in the law on assisted suicide point to the way legislation originally introduced to help terminally ill people in Holland and Belgium has now been extended to disabled babies. Do you agree or disagree with the following statements?”

Statements	Agree	Disagree	Don't know
If assisted suicide and euthanasia were legalised for terminally ill people in Britain it would inevitably be extended eventually to other groups such as the disabled.	42%	31%	28%
Assisted suicide and euthanasia should not be restricted to just the terminally ill and should be available for any person of any age and with any condition who requests it or whose family request it.	22%	53%	25%
Hospitals should be able to administer lethal drugs to end a patient's life if there is no prospect of a recovery.	49%	25%	27%
Changing the law on assisted suicide and euthanasia is likely to increase abuse of the elderly and disabled.	41%	29%	30%
The case of Harold Shipman, who is thought to have murdered up to 250 of his patients, shows that any system permitting assisted suicide could be open to abuse by people entrusted with overseeing patient safety.	59%	20%	22%

The impact of the Harold Shipman case on public perceptions of assisted dying was also explored in an earlier ComRes survey on behalf of CARE from 2012.<sup>473</sup> Contrary to the results of the later poll above, this found that the largest group (45%) disagreed that it would be foolish to legalise physician-assisted suicide in the wake of the Harold Shipman case, with 39 per cent agreeing and 16 per cent stating they did not know.

#### Assisted Suicide (Scotland) Bill

Results of a 2015 survey of the Scottish public that was commissioned by My Life, My Death, My Choice – an organisation campaigning for the Assisted Suicide (Scotland) Bill – and carried out by Progressive Partnership, found that a significant majority believed that the Bill becoming law was an important issue to them.<sup>474</sup> Out of a total of 1,006 adults who were asked “On a scale of 0 to 10, where 0 is not at all important and 10 is extremely important, how important an issue is it for you that the Assisted Suicide (Scotland) Bill becomes law?”, 78 per cent said it was of either “high” or “middling” importance, with 15 per cent saying it was of low importance and 7 per cent saying they did not know.

Similar to the surveys listed above a 2015 poll from CARE, conducted by ORB International and reported in the *Glasgow Herald* newspaper, looked both at agreement in Scotland with the principle of assisted suicide and then whether support changed on hearing different arguments.<sup>475</sup> The poll found that 35 per cent strongly agreed with the principle of assisted dying; 38 per cent agreed with the principle; 8 per cent disagreed with the principle; and 7 per cent strongly disagreed. Twelve per cent (12%) did not know. However, a number of participants (percentages given below) who initially supported it are reported to have changed their minds when presented with opposing arguments (no supportive arguments were presented):

- Risk that people will feel pressurised into ending their life early so as not to be a financial or care burden on loved ones – 22%
- Changes in the law in other countries have led to “a steady increase in the number of cases and spread of the practice to involve people with chronic but not fatal diseases, disabled people, children as well as those with mental illnesses and dementia” – 23%
- In Oregon there are “22 recorded cases of people regurgitating their lethal prescription and six have regained consciousness and not been counted as assisted suicide deaths” – 13%
- End-of-life care would be likely to worsen under financial pressures because it costs on average £3,000 to £4,000 a week to provide in-patient hospice care, but just a one-off cost of £5 to pay for the drugs which would help them commit suicide – 12%
- Doctors and disability rights advocacy groups oppose assisted suicide – 18%

### Disability and assisted dying

Views on the provisions of the Assisted Dying Bill have also been sought from disabled people in a number of polls. A 2013 YouGov survey, again commissioned by Dignity in Dying, found that 79 per cent supported assisted suicide with the safeguards of the Bill and 74 per cent would want the option available to themselves.<sup>476</sup> Assisted suicide in circumstances where an individual was not terminally ill but suffering from an incurable disease received majority overall support at 56 per cent. On the position of disability rights groups, 46 per cent thought that they should be neutral on the issue and 36 per cent believed they should support legalisation.

A 2012 ComRes telephone poll for ALERT, an anti-assisted dying pressure group, asked 1,000 people in the UK whether “if assisted suicide were made available on the NHS, do you think that this would make elderly or disabled people feel that their lives were less valued or more valued?”. Of the respondents, 33 per cent said they would be “more valued” compared to 37 per cent who said “less valued” and 8 per cent who believed it would make no difference. There were, however, differences between age groups with older respondents more likely to report that it would make disabled people feel “less valued” than younger respondents.<sup>477</sup>

In 2011 the disability charity Scope explored the levels of concern that disabled people had towards a change in the law to allow assisted suicide more generally, not in relation to the Bill or specifically in relation to either a terminal illness or an incurable illness.<sup>478</sup> In response to the question “Helping another person to commit suicide is currently against the law. How concerned or otherwise would you be about a change in the law to legalise assisted suicide?”, 53 per cent were either very or slightly concerned while 35 per cent were either not very concerned or not at all concerned. The survey also highlighted that more people would be concerned about the pressures on the lives of others rather than their own; if there was a change in the law 35 per cent of respondents would be concerned about pressure to end their own life prematurely; 70 per cent would be concerned about the same pressure being placed on other disabled people; and 56 per cent would be concerned that it could be detrimental to the way that disabled people are viewed by society as a whole.

A more recent Scope survey from July 2014, this time conducted by Opinium Research, of 1,005 disabled people in the UK, found that 64 per cent of disabled people and 72 per cent of young disabled people were concerned about moves to legalise assisted suicide.<sup>479</sup> Other findings again highlighted the specific concerns of this group and found that 62 per cent had concerns that legislative change in this area would put pressure on disabled people to end their lives prematurely and 55 per cent were concerned that individuals may choose it so as to not be a burden on friends, relatives or caregivers. For 55 per cent of respondents, the



current prohibition on assisted suicide protected vulnerable people from pressure to end their lives.

### Religion

A 2011 Ipsos Mori Poll on behalf of the Richard Dawkins Foundation for Reason and Science canvassed the opinions of UK adults who identified as Christians on a range of views, including assisted dying.<sup>480</sup> When asked the extent to which they agreed or disagreed with the statement “it should be legal to assist the suicide of a terminally ill adult patient who has clearly and consistently expressed the wish to die and is considered by doctors to be mentally and emotionally competent to make the decision”, three in five (59%) either strongly or tended to agree against 21 per cent who strongly or tended to disagree.

Two surveys in 2013 further explored the attitudes to assisted dying amongst individuals who identify as religious. A survey commissioned by Interfaith Leaders for Dignity in Dying (IFDiD) found that 18 per cent of the 1,247 people in the sample who had identified themselves as belonging to a religion opposed the legalisation of assisted dying with the safeguards proposed in the Assisted Dying Bill.<sup>481</sup> Respondents who attended services more than once a week were more likely to be opposed than those who attended services several times a month.

The YouGov survey of 4,437 people for the Westminster Faith Debates, discussed above, analysed the responses to the question of whether the law should be changed to give people with incurable diseases the right to ask close friends to help them commit suicide, by the different major religions. This highlighted that there was at least majority support for a change in the law across all included religions, with the notable exception of Hindus and Muslims.<sup>482</sup>

## 12. Other quantitative and qualitative research

Although there have been numerous polls and surveys of the public on their views on assisted dying, there has been less academic or qualitative research done with the public or patients to explore underlying beliefs associated with assisted dying.

### Assisted dying in dementia

Research published in 2007 examined the public’s views on life-sustaining treatments and euthanasia in the face of dementia by means of a cross-sectional questionnaire survey.<sup>483</sup> Participants were recruited from a variety of sources in London and the South East of England, including train and underground stations, shopping centres, and GP surgeries. Where individuals did not have time to complete the questionnaire at the time they could take it away and return by it post. In total there were 725 completed questionnaires, with a response rate of 71 per cent.

The questionnaire featured three plain English scenarios depicting mild, moderate and severe dementia. The sample was asked whether, in each of these situations and in respect of themselves or their partners, they would wish for four different life sustaining treatments – resuscitation, life support, tube-feeding, antibiotics for a chest infection – and three life-ending decisions – being allowed to die by withholding treatment, “euthanasia by friend/family member” and “physician-assisted suicide”. In the article euthanasia is referred to as being “helped to die by a friend/relative” while “physician-assisted suicide” is referred to as “to be helped to die by a doctor”.

With respect to life-sustaining interventions, the authors found that individuals were more likely to prefer therapeutic interventions for their partners than themselves and less likely to want life-sustaining treatments for either themselves or their partners as the severity of dementia increased.

There was a similar pattern with respect to life-ending decisions, with individuals less likely to wish these for their partners than for themselves and support for interventions increasing with the severity of the condition. The study figures for euthanasia by friend or family member and physician-assisted dying are provided below in Table 12.

**Table 12 – Public agreement with life-ending interventions for themselves or their partners in dementia<sup>484</sup>**

Life-ending intervention	Mild dementia		Moderate dementia		Severe dementia	
	Individual (% – yes)	Partner (% – yes)	Individual (% – yes)	Partner (% – yes)	Individual (% – yes)	Partner (% – yes)
Euthanasia by friend or family	45.5	42.5	44.2	44.2	50.9	48.7
Physician-assisted suicide	55.3	52.3	55.2	52.5	59.5	57.4

The study also looked at differences in perspectives between different ethnic minority groups and found that white respondents were less likely to want treatment than black, Asian and other ethnicities. Similarly, white respondents were significantly more likely to agree with all life-ending decisions in all severities of dementia than black, Asian or other ethnicities.

### Views of the terminally ill on assisted dying

A study from 2006 looked at some of the issues associated with euthanasia from the perspective of patients who were terminally ill.<sup>485</sup> The authors conducted non-directed interviews with 41 people, of whom 18 voluntarily discussed the subject of euthanasia in depth and at length. Although the authors accept that the study had a number of weaknesses, several key themes came out of the interviews connected to both support for assisted dying and opposition:

- Arguments supporting voluntary euthanasia or assisted suicide:
  - a need to control events;
  - fear of uncontrollable pain;
  - experience of witnessing death on a shared ward and wanting to avoid the indignity of death;
  - dread of cognitive impairment;
  - concern voiced by some about not wanting to be a physical or financial burden to others in conjunction with other reasons for wanting assisted dying;
  - those who spoke most passionately of a need for a change in law were also those who had seen others die.
- Arguments voiced against change in the law:
  - fear that any legislation may be misused – one man would welcome it for himself but hesitated to recommend it as national policy;
  - others shared concerns about potential for abuse but concluded each case should be decided on its own merit.

A systematic review, of which this study formed part, looked at international evidence on the views on assisted dying amongst the broader group “non-health professionals”.<sup>486</sup> The concerns highlighted in the 2006 study above were echoed in the qualitative synthesis of this wider international research. The authors found that despite the different legal, cultural and organisational contexts, people expressed some common themes and concerns around poor quality of life, the desire for a good quality of death (including choice and control), concerns about potential for abuse and the importance of an individual’s stance (including religious or moral views and personal experience).

## Part 5: Comparative table of recent UK legislative proposals

None of the legislative proposals considered in the UK would have permitted euthanasia: the draft bills would have legalised physician-assisted suicide only.

	<b>Assisted Dying Bill – “the Falconer Bill”, 2014</b>	<b>Assisted Dying (No. 2) Bill – “the Marris Bill”, 2015</b>	<b>Assisted Suicide (Scotland) Bill 2015</b>
	England and Wales only	England and Wales only	Scotland only
Eligibility criteria	<p><b>The patient must:</b></p> <ul style="list-style-type: none"> <li>– be at least 18 years old;</li> <li>– have been resident of England or Wales for at least a year;</li> <li>– be terminally ill and reasonably expected to die within six months;</li> <li>– have a clear and settled intention to end their life reached voluntarily and on an informed basis;</li> <li>– have capacity (in accordance with the Mental Capacity Act 2005).</li> </ul>	<p><b>The patient must:</b></p> <ul style="list-style-type: none"> <li>– be at least 18 years old;</li> <li>– have been resident of England or Wales for at least a year;</li> <li>– be terminally ill and reasonably expected to die within six months;</li> <li>– have a clear and settled intention to end their life reached voluntarily and on an informed basis;</li> <li>– have capacity (in accordance with the Mental Capacity Act 2005).</li> </ul>	<p><b>The patient must:</b></p> <ul style="list-style-type: none"> <li>– be at least 16 years old;</li> <li>– be registered with a medical practice in Scotland;</li> <li>– have an illness that is either terminal or life-shortening OR a condition that is progressive and either terminal or life-shortening;</li> <li>– see no prospect of improvement in their quality of life;</li> <li>– after reflection, conclude that their quality of life is unacceptable;</li> <li>– have capacity (in accordance with the Adults with Incapacity (Scotland) Act 2000) and not be suffering from any mental disorder that might affect the making of a request.</li> </ul>
The request	<p><b>The request must:</b></p> <ul style="list-style-type: none"> <li>– be made in writing;</li> <li>– be signed by a witness (who cannot be a relative or involved in that person’s care);</li> <li>– be countersigned by two doctors.</li> </ul>	<p><b>The request must:</b></p> <ul style="list-style-type: none"> <li>– be made in writing;</li> <li>– be signed by a witness (who cannot be a relative or involved in that person’s care);</li> <li>– be countersigned by two doctors.</li> </ul>	<p><b>The request must:</b></p> <ul style="list-style-type: none"> <li>– be made as an initial, witnessed, preliminary declaration that assisted suicide is something the individual is willing to consider (this can be done before the individual becomes terminally ill);</li> <li>– be made as a first formal request in writing at least 7 days after the making of the preliminary request;</li> <li>– be made as a second formal request in writing at least 14 days after the making of the first;</li> <li>– be endorsed by two doctors.</li> </ul>
Medical involvement	<p><b>The attending physician (usually the individual’s own GP or specialist consultant) must:</b></p> <ul style="list-style-type: none"> <li>– confirm that the patient meets the eligibility criteria;</li> <li>– be satisfied that the patient has been informed of all their options, including palliative and hospice care available;</li> <li>– deliver the medication at the patient’s request (after a cooling off period of 14 days); prepare it for self-administration;</li> <li>– stay with the person until the time of death; or authorise in writing another physician, or a nurse, to do so.</li> </ul> <p><b>The independent doctor (from a different practice or clinical team) must:</b></p> <ul style="list-style-type: none"> <li>– also confirm that the patient meets the eligibility criteria;</li> <li>– be satisfied that the patient has been informed of all their options, including palliative and hospice care available.</li> </ul>	<p><b>The attending physician (usually the individual’s own GP or specialist consultant) must:</b></p> <ul style="list-style-type: none"> <li>– confirm that the patient meets the eligibility criteria;</li> <li>– be satisfied that the patient has been informed of all their options, including palliative and hospice care available;</li> <li>– deliver the medication at the patient’s request (after a cooling off period of 14 days); prepare it for self-administration;</li> <li>– stay with the person until the time of death; or authorise in writing another physician or a nurse, to do so.</li> </ul> <p><b>The independent doctor (from a different practice or clinical team) must:</b></p> <ul style="list-style-type: none"> <li>– also confirm that the patient meets the eligibility criteria;</li> <li>– be satisfied that the patient has been informed of all their options, including palliative and hospice care available.</li> </ul>	<p><b>The doctor must:</b></p> <ul style="list-style-type: none"> <li>– confirm that the patient meets the eligibility criteria;</li> <li>– confirm that the patient’s conclusion that their quality of life is unacceptable is not inconsistent with the facts known to them;</li> <li>– refer the patient to another practitioner, who must also confirm that the person meets the eligibility criteria, and that the patient’s conclusion that their quality of life is unacceptable is not inconsistent with the facts known to them.</li> </ul> <p>Neither doctor would be responsible for providing the lethal dose of medication. This would be the responsibility of a <b>licensed facilitator</b>, a new role created by the Bill who must also provide, before during and after the act of suicide such practical assistance and comfort and reassurance as the person wishes, and be with the person at the time of death.</p>

Conscientious objection clause?	Yes	Yes	No
Court involvement	Amendments passed at committee stage would require a judge of the high court to review any requests for assisted dying and to confirm that the patient's wish was genuine and not coerced.	<b>A judge of the High Court (Family Division) must:</b> <ul style="list-style-type: none"> <li>– review all applications for assisted dying, after two doctors had confirmed that the individual met the eligibility criteria for assisted dying;</li> <li>– rule on all requests within 14 days.</li> </ul>	
Regulation	The Bill contained provisions which would enable the Secretary of State to determine how assisted deaths should be recorded and monitored.	The Bill contained provisions which would enable the Secretary of State to determine how assisted deaths should be recorded and monitored.	The licensed facilitator must report all cases to the police. The Bill contained provisions for the Scottish Government to appoint a body to be responsible for licensing and regulation.
Outcome	Fell at committee stage in March 2015 when Parliament prorogued for the General Election.	Fell at second reading in September 2015 by 330 votes to 118.	Fell at stage one consideration in the Scottish Parliament by 82 votes to 36; with no abstentions.



## Chapter 4

# International evidence on assisted dying

## Chapter 4

### International evidence on assisted dying

Evidence from the small number of jurisdictions where assisted dying is currently legally practised is frequently cited in the broader debate on the issue. It reveals much about how assisted dying works in reality, from the most practical aspects such as the numbers of people seeking assistance in ending their lives, and the methods used to achieve this; to the broader issues of the reasons why people seek assisted dying, and adherence to the law by the professionals involved in the process.

As in the broader debate on assisted dying, it was anticipated that participants in the events would refer to the available international evidence, and so it was crucial to have a detailed understanding of the laws permitting assisted dying currently in force around the world. This section of the report outlines the relevant legal context in those jurisdictions where assisted dying is legal; examines the data from those jurisdictions; and explores some of the research connected with its operation through the analysis of some common features. Evidence explored will come from the Netherlands, Belgium, Oregon and Switzerland, where assisted dying has been established for a number of years. Information about other countries where assisted dying is lawful can be found in the comparative table at the end of this chapter.

#### Part One – An overview on assisted dying

Legislation permitting euthanasia and assisted suicide has existed in the Netherlands since 2001 (Termination of Life on Request and Assisted Suicide Act); Belgium since 2002 (Belgian Act on Euthanasia); and Luxembourg since 2009 (Law on the Right to Die with Dignity).<sup>487</sup> The legislation in these jurisdictions permits competent individuals who make a voluntary and persistent request to have physician-administered euthanasia. In the Netherlands, assisted suicide is also permitted. In Belgium, although the law only explicitly provides for euthanasia, physician-assisted suicide is not prosecuted, provided the conditions and procedures for euthanasia have been complied with. Access to assistance is not restricted to those with terminal illnesses, but extends to individuals experiencing “constant and unbearable” physical or psychological suffering, which cannot be relieved in any other way.

The Death with Dignity Act, which permits assisted suicide, was passed in Oregon in 1994, and legislation closely modelled on it was passed in Washington in 2008 (also known as the Death with Dignity Act) and Vermont in 2013 (the Patient Choice and Control at the End of Life Act). Under this law, competent adults who have been diagnosed with a terminal illness, and who are reasonably expected to die within six months, may request a prescription for a lethal substance from a physician.

The law in Switzerland is unique in that whilst there is no specific legislation on assisted dying, assisted suicide is legal in the absence of selfish motives under s.115 of the Swiss Criminal Code. Anyone who incites or assists another to commit suicide for selfish motives will still be liable for conviction for murder.

The most recent piece of legislation on assisted dying is the End of Life Option Act, which was passed in California in October 2015 in an extraordinary session called by the Governor.<sup>488</sup> The law is very closely modelled on Oregon’s Death with Dignity Act, and would allow physician-assisted suicide for terminally ill California residents over the age of 18, who have the capacity to make medical decisions. The Act also creates a felony offence of pressuring someone to make a request, or forging a request.<sup>489</sup> The Act is due to come into force on 1 January 2016, and will expire after ten years unless extended.<sup>490</sup> It is subject, however, to potential legal challenge through an attempt to petition for a ballot referendum.<sup>491</sup>

Elsewhere, there are a number of court rulings which have been supportive of assisted dying. Most recently, in February 2015 the Supreme Court of Canada ruled on assisted dying in *Carter v Canada*. The Court unanimously held that the Criminal Code prohibition on assisted suicide unjustifiably infringed various rights enshrined within the Charter of Rights and Freedoms, to the extent that it prohibited physician-assisted death for competent, clearly consenting adults with “grievous and irremediable” medical conditions causing intolerable suffering. A key argument in the Court’s reasoning was that the prohibition deprived some individuals of life, as it had the effect of forcing some individuals to end their life prematurely, out of fear that they would be incapable of doing so once their disease progressed. The Court suspended its ruling for 12 months to allow Parliament and provincial legislatures to respond, should they choose to do so.<sup>492</sup> In July 2015 it was announced that a federal review panel had been appointed and had launched a consultation on options for assisted dying processes.<sup>493</sup> The Court’s ruling followed the passing of Bill 52 – the “Dignity with Dying Law” – by the Quebec National Assembly. This law was due to come into effect in 2015, and would permit competent adults to request medical aid in dying, provided certain criteria were met.

Earlier court rulings in the USA on assisted dying include the Montana Supreme Court’s ruling in January 2009, that while the state’s constitution did not guarantee a right to physician-assisted suicide, there was “nothing in the Montana Supreme Court precedent or Montana statutes indicating that physician aid in dying is against public policy”.<sup>494</sup> This judgment has yet to be tested in a higher court. In January 2014 a District Court in New Mexico held that terminally ill, mentally competent patients have a right to aid in dying under the New Mexico state constitution,<sup>495</sup> a decision which was overruled by the New Mexico Court of Appeals in August 2015, when they held that “aid in dying is not a fundamental liberty interest under the New Mexico Constitution”.<sup>496</sup>

In 1997, Colombia’s highest court, the Constitutional Court, ruled that a doctor could not be prosecuted for assisting a terminally ill, consenting individual to end his or her life.<sup>497</sup> The Court urged the Colombian Congress to debate the issue and to adopt legislation, but the status of the law on assisted dying remained unconfirmed for many years. In February 2015, the Court set a 30 day deadline for the Ministry of Health to implement euthanasia protocols for doctors. They stated that “without clear rules and precise procedures, doctors do not know exactly when they are committing a crime and when they are contributing to the realisation of a fundamental right”.<sup>498</sup>

In April 2015 it was reported that the Colombian Ministry of Health had drawn up such guidelines. Under the guidelines, only competent adults with a terminal illness would be able to request the procedure, or, if the patient was unconscious, relatives would have to present audio, video, or written proof that he or she wanted to be assisted to die.<sup>499</sup> The individual concerned would have to express their desire for assistance in dying to a doctor, who must present the individual with all available treatment options. If the patient’s wish persists, the doctor must present the case to a specialist scientific committee comprised of a medical expert, a lawyer, and a mental health professional. This committee would have ten days in which to reach a decision on whether the patient met the eligibility requirements. If the committee approves the procedure, it must confirm that decision with the patient. If the patient wishes to continue, the hospital would have 15 days in which to comply.<sup>500</sup>

In some jurisdictions where the law is silent on the issue of assisted dying, whether the practice is technically legal or illegal will often vary and be unclear. The focus in this section, however, will be on jurisdictions where assisted dying has been explicitly legislated for or ruled on by a court.



### Where else has assisted dying been considered?

- Euthanasia was briefly legal in Australia's Northern Territory in 1995, when its legislative assembly passed the Rights of the Terminally Ill Act. Two years later, the Australian federal parliament passed the Euthanasia Laws Act, which rendered the Rights of the Terminally Ill Act invalid by amending the constitutional rights of states.<sup>501</sup> In the interim, four people made use of its provisions.
- Draft bills on assisted dying were considered in England and Scotland in the 2014-15 parliamentary session. The bill for Scotland was rejected in 2015. Later that same year, a private member's bill was considered and rejected by the House of Commons. Details of this can be found in chapter 3.
- In March 2012, a private member's bill, the End of Life Choices Bill was introduced into the New Zealand Parliament. It was withdrawn in October 2013 ahead of a General Election.<sup>502</sup> A challenge to New Zealand's prohibition on assisted suicide was rejected by the High Court in June 2015, where the judge held that the law could only be changed by parliament passing legislation.<sup>503</sup> The following month, the Parliament's Health and Select Committee announced an inquiry into public attitudes towards voluntary euthanasia.<sup>504</sup>
- In 2012, the Tasmanian Assembly rejected a private member's bill, the Voluntary Assisted Dying Bill.<sup>505</sup>
- The Irish Supreme Court rejected a challenge to Ireland's prohibition on assisted suicide in April 2013, where it was held that "there is no constitutional right to commit suicide or to arrange for the determination of one's life at a time of one's choosing".<sup>506</sup>
- Throughout 2014, there were various legislative measures on assisted dying under consideration in the USA, including Connecticut,<sup>507</sup> New York,<sup>508</sup> and New Jersey.<sup>509</sup>
- In the summer of 2015, Germany's Parliament, the *Bundestag*, received two draft bills on assisted dying. One bill would criminalise the provision of assisted dying services for money; the other would go further and remove all legal hurdles to assisted suicide so that any adult meeting legal criteria who has been counselled by a doctor would have the right to die.<sup>510</sup>
- In April 2014, the High Court of Pretoria, South Africa, ruled that the doctor of a 65-year-old man with cancer should be immune from prosecution if he assisted him in ending his life. The judge insisted that this ruling applied only to the individual in this case, and that all future cases would be considered on their merits. The individual in question died of natural causes shortly after the court order was issued.<sup>511</sup>

## Part Two: The Netherlands

### 1. The law

#### Termination of Life on Request Act 2001

- The **patient** must be aged 18 or over; be “decisionally competent”; and be experiencing unbearable physical or psychological suffering, with no prospect of improvement.
- Patients aged between 16 and 18 who have capacity may also request euthanasia or assisted suicide, although their parents must also be consulted. Patients aged between 12 and 16 may also make a request if they are deemed to have capacity, but they must also have parental consent.
- The **request** must be voluntary and well-considered and made on the basis of all available information about the disease, disease progression, and available treatment and care options.
- The **attending physician** must be satisfied that the patient’s suffering is unbearable, with no prospect of improvement, and that their request is voluntary and well-considered. They must also have consulted with at least one other **independent physician**, who must see the patient and give a written opinion on whether they meet the eligibility criteria.
- The **attending physician** must exercise “due medical care and attention” in ending the patient’s life.
- The attending physician must report the death to the municipal coroner, who will then inform one of five **regional review committees** who will assess whether the law has been complied with.

It is important to acknowledge the unique legal context from which the Dutch law emerged. The passing of the Termination of Life on Request Act effectively codified a permissive practice that had existed for many years, and which had been developed through a series of judicial decisions and professional guidelines. The legal debate concerning euthanasia in the Netherlands began with the *Postma* case in 1973, where a physician assisted in the death of her mother, who had made repeated requests for euthanasia. Whilst the physician was convicted for murder, the court’s judgment acknowledged that a physician does not always have to keep patients alive when faced with pointless suffering.<sup>512</sup> This principle was developed through a number of cases throughout the 1980s, culminating in the *Schoonheim* case in 1984, where the Dutch Supreme Court acquitted a physician who had performed euthanasia on the explicit request of a 95-year-old patient who had been experiencing a serious deterioration of health. The Court concluded that the physician had acted out of necessity in alleviating “unbearable suffering”,<sup>513</sup> as it was only possible to do so by ending the patient’s life.<sup>514</sup> Subsequent cases in the 1990s confirmed that “unbearable and hopeless” psychological suffering, even in the absence of physical illness, was legitimate grounds for a doctor to assist suicide,<sup>515</sup> but that even then, there must be medical grounds for that suffering.<sup>516</sup>

In Dutch law, a patient aged between sixteen and eighteen who is deemed to have capacity may request euthanasia or assisted suicide. Their parents must be consulted, but lack a right of veto. Patients between the age of twelve and sixteen must also be deemed to have capacity, but their parents must give consent as well.

Dutch law also recognises that there may be circumstances where it is permissible to deliberately end the lives of severely disabled neonates. This is distinct from the law on euthanasia, and is governed by the Groningen Protocol, which sets out the criteria which should be taken into account by doctors when ending the life of neonates who are suffering from a hopeless and unbearable condition.<sup>517</sup>

## 2. Data

In 2013, the Dutch regional euthanasia review committees – the bodies responsible for assessing compliance with the law – received 4,829 notifications of euthanasia and assisted suicide: 4,501 cases of euthanasia; 286 cases of assisted suicide; and 42 cases involving a combination of the two (usually where the physician makes an active intervention if the time to death is too long with assisted suicide).<sup>518</sup> This has more than doubled from the 1,882 who made use of the law when it first came into force in 2002<sup>519</sup> and represents 3.4 per cent of all deaths in 2013 (total deaths: 141, 245).<sup>520</sup>

In the Netherlands it is estimated that physicians are confronted with requests to help patients die, on average, two to three times a year. There are some estimates that there are about ten times more requests for assisted suicide than actual cases, because many people raise the issue for reassurance that it could be an option for them in the future.<sup>521</sup>

## 3. Methods and complications

The Royal Dutch Medical Association (KNMG) and the Royal Dutch Association for the Advancement of Pharmacy (KNMP) published joint guidance on performing euthanasia and assisted suicide procedures in August 2012, which is relied upon by the regional review committees in their consideration of whether a physician has exercised due medical care and attention in assisting the individual.<sup>522</sup> The guideline lists which substances, doses, and methods should be used, as well as explicitly listing a number of substances, doses, and methods which should not be used.

For euthanasia, the guideline recommends intravenous administration of an anaesthetic agent to induce coma, followed by intravenous administration of a paralysing agent (or muscle relaxant). The use of the coma-inducing substance in its correct dose is crucial in order to ensure the patient cannot perceive the effects of the paralysing agent (muscle relaxant). Barbiturates (which act as depressants to the central nervous system) are generally the preferred method of assisted suicide. They can produce a wide spectrum of effects, from mild sedation to total loss of consciousness/coma. When used in sufficiently high dosage, they depress the respiratory system, which, together with vascular or cardiac shock, will lead to death.

A 2000 review analysed clinical problems with administration in 649 cases of euthanasia and assisted suicide in the Netherlands.<sup>523</sup> In 114 cases, the physician's intention was to provide assistance with suicide, and in 535, the intention was to perform euthanasia. Complications occurred in 7 per cent of cases of assisted suicide, and problems with completion (e.g. a longer than expected time to death; failure to induce a coma; induction of a coma followed by awakening of the patient) occurred in 16 per cent of cases; complications and problems with completion occurred in 3 per cent and 6 per cent of cases of euthanasia, respectively. The most commonly reported problems with oral administration were nausea or vomiting. The most commonly reported problem with parenteral (i.e. intravenous or intramuscular) administration was locating a vein for injection.

The complication of a longer than expected interval between the administration of a drug and death was reported more commonly in cases of assisted suicide than euthanasia. This often led to physicians intervening and administering the lethal dose themselves, making it euthanasia rather than assisted suicide which caused the death of the patient. Doctors reported intervening in 21 out of the 114 reported cases of assisted suicide studied. In the majority of cases (12) this was because the interval between administration and death was too long (9 cases); the patient did not become comatose after taking the first drug (1 case); or the patient awoke from coma (2 cases). In five other cases, the physician intervened because the patient had difficulty taking all the oral medication, for example, they fell asleep before finishing it, or regurgitated it. In the remaining four cases no specific reason was given for the doctors' intervention.

It has been suggested that the fact that problems of any type are more frequent in cases of assisted suicide than in cases of euthanasia may explain the preference of Dutch doctors to be involved in euthanasia procedures rather than assisted suicide, as they are able to control the act of ending life.<sup>524</sup>

## 4. Eligibility

### “Unbearable suffering”

In the Netherlands, in order to be eligible for assistance in dying, the individual must have unbearable physical or psychological suffering, with no prospect of improvement. The regional review committees define “no prospect of improvement” as when the disease or disorder causing the suffering is incurable, and there is no realistic alternative way of alleviating the patient’s suffering. This judgement is made by the physician, with consideration of the severity of the diagnosis and prognosis, and the possible improvements that can realistically be achieved by palliative care and other treatments. It does not mean that the patient *must* undergo every possible form of palliative care or other treatment. Patients who are suffering unbearably may refuse care or treatment because they may consider that the positive effects of treatment do not outweigh the negative effects.

The issue of whether that suffering is “unbearable” is a more subjective judgement. The question is not whether people in general would find that level of suffering unbearable, but whether it is unbearable to that particular patient, “in the context of his life history and values”.<sup>525</sup>

The KNMG makes it clear that the patient’s suffering must always be rooted in medically classifiable somatic or psychological illness; and that providing euthanasia or assisted suicide when there is no “unbearable suffering” with a medical basis falls outside the scope of the legislation. However, there is no requirement that the medical condition be life-threatening, and so multiple conditions associated with ageing could cause unbearable suffering with no prospect of improvement. The KNMG has indicated that increasing numbers of physicians are approached by people of advanced age and multi-morbidity, the accumulation of which would mean that they meet the requirements of the law.<sup>526</sup>

### Physical vs. psychological suffering

In 2013, the vast majority of cases in the Netherlands involved individuals with physical conditions.<sup>527</sup> The most common condition for which assisted dying was sought (74.3%) was cancer, with neurological disorders (6%) and “multiple geriatric syndromes” (5.9%) coming second and third respectively. There has been an increase in the number of cases involving dementia: in 2013, patients with dementia formed 97 cases reported to the committees, over double that of 2012, when 42 cases were reported.

The country has also seen an increase in the number of cases involving mental disorders. Mental disorders were cited as the main condition in 42 cases in 2013, compared with 14 in 2012 and 13 in 2011. The annual report concludes that there “appears to be an increase in willingness among physicians to carry out euthanasia and assisted suicide in cases involving a mental disorder”.

The regional review committees advise that requests for assisted dying on the grounds of a mental disorder must be approached with “particular caution” and it appears that Dutch physicians are far more reluctant to grant euthanasia and assisted suicide requests in cases involving psychological suffering than they are in cases involving physical suffering. A study of over 2,000 Dutch physicians found that less than half (34 per cent) of physicians found it conceivable that they would grant a request for euthanasia or physician-assisted suicide in patients with psychiatric disease, compared to 85 per cent who would find it conceivable to grant a request for patients with cancer.<sup>528</sup> The authors concluded that little is known about physicians’ opinions on euthanasia and assisted suicide in cases of psychiatric illness – but that one study from 1997 indicated that the main reasons for refusing euthanasia or assisted suicide for psychiatric patients were doubts about whether all treatment options had been exhausted, and whether the suffering was unbearable and hopeless.

Another study which assessed how doctors judge suffering in the context of euthanasia asked various different doctors whether they considered the suffering of a patient to be unbearable in a “standard case” – where a patient with physical suffering had a limited life-expectancy – alongside other cases where the suffering was mainly rooted in psychological or existential suffering.<sup>529</sup> It found that for a patient whose suffering was mainly rooted in

physical symptoms, nearly all respondents were convinced that the patient was suffering unbearably. However, where physical suffering was less, and psychological suffering was more prominent, fewer respondents were convinced that the patient was suffering unbearably. In particular, GPs were less likely to think the suffering was unbearable than consultants or members of euthanasia review panels.

In 2012, the End-of-Life Clinic (SLK) was established by a Dutch right-to-die organisation, with the aim of serving patients unable to find a doctor willing to assist them. As was anticipated in the founding of the clinic, a large number of cases involved patients with less common situations, such as psychiatric and psychological conditions. Here too, patients with psychological conditions were far less likely than patients with physical conditions to have their request granted – 5 per cent of requests on the grounds of psychological conditions were granted compared to 32.8 per cent of requests on the grounds of somatic conditions.<sup>530</sup>

### **“Tired of life”**

Being “tired of life” is defined as “suffering caused by the prospect of having to continue living with a very poor quality of life, not predominantly caused by a physical or psychiatric disease”.<sup>531</sup> In the case of Dr Boudewijn Chabot, who assisted a healthy 50-year-old woman who did not want to go on living after the death of her two sons, the Dutch Supreme Court held that someone who is tired of living can suffer unbearably, if that is how that person perceives it. Subsequent jurisprudence made clear that in order for a physician to assess the extent of suffering, it must have a medical dimension.<sup>532</sup> However, the Royal Dutch Medical Association published a position paper in 2011 stating that whilst there must be medical grounds for suffering – including being tired of life – this need not be the main cause.<sup>533</sup>

Although some cases of euthanasia and assisted suicide have been reported (and approved) in patients suffering unbearably from an accumulation of factors and conditions, no cases in which suffering was not predominantly caused by medical grounds have been reported.<sup>534</sup> However, requests for euthanasia and assisted suicide from people who are “tired of life” seem to persist, and there are some estimates that Dutch physicians receive up to 400 requests for assistance in dying from older people who are “tired of living” per year.<sup>535</sup>

As with requests for euthanasia and assisted suicide on the grounds of a mental disorder, Dutch physicians appear to be less willing to grant requests for patients who are “tired of life” than they would for patients with a clearly defined physical illness. One survey of over 400 doctors found that 30 per cent had received an explicit request for euthanasia or assisted suicide in the absence of a severe disease (of which most of those made to GPs were made by single people aged 80 years or over), but that only 3 per cent had actually granted such a request.<sup>536</sup> In a separate study of over 2,000 Dutch physicians, it was found that only 27 per cent of them would find it conceivable that they would grant a request for euthanasia or physician-assisted suicide in a patient who was tired of living.<sup>537</sup>

A recent survey of the Dutch public’s attitudes to assisted suicide for older persons who are “tired of living” found that the respondents to the survey may not be fully representative of the Dutch public, and that those in favour of assisted dying for the elderly who are “tired of life” were more likely to be higher educated, have less trust in their physician to comply with their wishes, and place greater value on autonomy and the ability to make their own medical decisions rather than accepting their physician’s. This led the authors to conclude that the persons who support assistance in dying for older people who are “tired of living” are not necessarily the same persons that are the subject of the debate. They suggested that society must be very careful to protect the most vulnerable from public opinions such as these.<sup>538</sup>

## 5. Request

### Presence of request

The evidence that exists indicates that the legal requirement for a request to precede assisted dying is respected in all reported cases. An evaluation of the first five years of legalised euthanasia and assisted suicide in the Netherlands found that death had been requested in all 10,319 reported cases.<sup>539</sup> A later study of reported cases from 2007 to 2009 found that physicians had met the criteria related to the presence of a request in all of the 7,487 cases.<sup>540</sup>

The reliance on self-reported information to assess compliance with the law means it is difficult to assess whether physician-assisted dying is being carried out in the absence of a request from a patient. Some studies have suggested that there are a number of cases of “termination of life without request” – sometimes referred to as non-voluntary euthanasia – where euthanasia is carried out without the explicit consent of the patient. A series of studies carried out by the Rummelink Commission in the Netherlands used stratified samples of death cases drawn from the central death registry, and sent questionnaires to all physicians who attended a death. Studies conducted in 1990, 1995, 2001 and 2005 all revealed cases of termination of life without request, ranging from 1,000 in 1990 to 550 in 2005.<sup>541</sup> The Commission studies found that in around half of these (on average, 52%), the decision had been discussed with the patient at a point in time when they were conscious and/or had capacity, or that the patient had expressed a wish for euthanasia in a manner that fell short of the legal requirement of an explicit request. A separate study indicated that unreported cases almost all involved the use of opioids and were not considered to be euthanasia by physicians.<sup>542</sup>

Dutch law does not require a request for assisted dying to be made in writing, but regional review committees note that a written directive can eliminate any uncertainty around the presence of the request.<sup>543</sup> A study of 158 reported euthanasia and assisted suicide cases found a written declaration in 97 per cent of cases.<sup>544</sup> Dutch law also recognises the validity of advance directives for assisted dying, providing that the wish was expressed and written down at a time when the patient was decisionally competent.

### Capacity

Dutch law requires the individual requesting assistance to be “decisionally competent”. Part of this requires the physician to inform the individual of their diagnosis, prognosis, and all possible options for treatment.

National data relating to the reasons for refusing requests for assisted dying can provide some indication of how effectively the criteria for capacity are applied. In 2010, Dutch physicians cited a lack of a well-considered request as the reason for not granting euthanasia requests in 16 per cent of cases.<sup>545</sup> This is reflected in the most recent annual study of data gathered by SCEN (Support and Consultation for Euthanasia in the Netherlands – a network of specially trained euthanasia consultants), which noted that when SCEN consultants found that due care criteria have not been met, the reason given in 39.4% of cases in 2011 was the lack of a well-considered request.<sup>546</sup> A 2005 study of Dutch GPs explored the characteristics of granted, withdrawn, and refused requests for euthanasia and assisted suicide and found that a “lesser degree of competence” had one of the strongest associations with the refusal of a request.<sup>547</sup>

In cases involving a request for assistance on the grounds of a mental disorder or dementia, the regional review committees note the importance of consulting “one or more experts”, including a psychiatrist, in addition to the statutorily mandated independent physician. With cases of dementia, the annual report of the regional review committees notes that the vast majority of these patients were in the initial stages of the disorder, still had “insight into their condition and its symptoms”, and were deemed to be decisionally competent. The report acknowledges that patients at a more advanced stage of the disorder are less likely to be decisionally competent. In these cases it is “essential” that there is a record of the patient expressing the wish for euthanasia in the past, namely a clear advance directive written by the patient when still decisionally competent. In 2013, all cases involving dementia were found by the review committees to have been handled with due care.<sup>548</sup>

### Depression

Depression is a concern in requests for euthanasia and assisted suicide because it is a potentially treatable and reversible condition which may affect a patient's capacity – in particular, the weight they give to positive and negative aspects of their situation and possible future outcomes. Considerable disagreement exists over the prevalence of depression in individuals seeking assisted dying and the influence it may have on the capacity to request assisted dying. Further complicating the matter is the fact that in the Netherlands, if depression is causing unbearable suffering which cannot be relieved, it may be legitimate grounds for assistance.

The Dutch regional review committees note that doctors should consider the presence of depression in patients, and whether this is adversely affecting their decisional competence. If there is any doubt, a psychiatrist will often be consulted in addition to the independent physician.<sup>549</sup> However, some evidence suggests that psychiatric consultation is rare – especially if the patient's own doctor is not a psychiatrist. A 2004 survey of Dutch psychiatrists found that just 36 per cent of respondents had been consulted at least once about a patient's request for euthanasia.<sup>550</sup> Extrapolating the evidence, it was estimated that the annual number of psychiatric consultations in euthanasia is around 400 – just 4 per cent of all requests.

A systematic review of studies reporting rates of depression in requests for and cases of euthanasia and assisted suicide in the Netherlands and Oregon found huge variation in estimates of the presence of depressive symptoms in people requesting euthanasia or assisted suicide. Between 8 and 47 per cent of patients requesting euthanasia or assisted suicide had depressive symptoms, and there were depressive symptoms in between 2 and 17 per cent of granted requests.<sup>551</sup> In the Netherlands, where the strongest data were from, the evidence shows that depression is significantly higher in refused than granted requests. The authors state that the evidence both shows that "depression is a significant factor in refusing euthanasia/PAS requests" and implies that "the Dutch system may be successful at screening out many requests motivated by depression". Two of the studies assessed also found that there was no significant difference in the rate of depression between euthanasia cases, and similar patients who had not made a request for euthanasia, leading the authors to suggest that depression is not necessarily correlated with the euthanasia request, but with the terminal and serious conditions these patients generally have.

A study in 2005 examined the presence of depressive symptoms in the final 24 hours of life, and again found that depressive symptoms were far higher in ungranted requests than granted requests: depressive symptoms were present in 12 per cent of ungranted requests and 2 per cent of granted requests.<sup>552</sup>

### Voluntariness

The individual seeking assistance must not have made their request under pressure or unacceptable influence from those around them.

It is notoriously difficult to assess whether some people have been coerced into making a decision. However, as with capacity, data relating to refused requests can indicate how the voluntariness criteria are applied. In 2005, 6 per cent of all ungranted requests were refused on the basis of the lack of a voluntary request.<sup>553</sup> It has also been reported that SCEN consultants find in about 3.5 per cent to 6.5 per cent of cases that the due care criteria have not been satisfied due to the lack of a voluntary request.<sup>554</sup>

A review of a random representative sample of reports submitted to regional review committees in the Netherlands in 2011 explored how doctors were satisfied that requests were voluntary. In 45 per cent of cases, it was the fact that the patient had made repeated requests. In 43 per cent of cases, this had been ascertained through personal conversations between the doctor and patient. A lack of indication of any pressure or influence convinced doctors in 37 per cent of cases.<sup>555</sup>

## 6. Physicians and the law

### Medical involvement

The Dutch law requires the involvement of at least two doctors: the “attending physician” and a second, independent doctor. In 2013, the attending physician was a general practitioner in 88.7 per cent of all cases. In 4.41 per cent they were hospital specialists, and in 3.99 per cent they were geriatricians.<sup>556</sup>

Dutch law requires the attending physician to consult another independent physician who must provide a written opinion on whether the due care criteria contained in the law have been met. This requirement does not mean that the two doctors need to agree, or that the independent physician must give permission to the attending doctor to assist in a person’s death. If the two disagree, the attending doctor must be able to demonstrate that he considered the independent physician’s findings and took account of them in reaching his own decision.

The independent physician is very often, but not always, a SCEN physician. SCEN stands for Support and Consultation Euthanasia Netherlands and is a network set up in 1999 with the aim of training doctors in medical, ethical, and legal aspects of euthanasia consultation, in order to provide competent and independent second physicians as consultants in euthanasia requests.

As noted above, in cases involving a request for assistance on the grounds of a mental disorder or dementia, the regional review committees note the importance of consulting additional experts, including a psychiatrist or geriatrician.

The physician must not let someone else administer or give the euthanasic agent to the individual, nor leave the patient alone with it. A physician who elects not to be present at the time of death (e.g., at the patient’s request) should make arrangements to be available should the prescribed drugs fail to have the intended effect. In two studies analysed in 2000, the doctor was continuously present in 52 per cent of cases of assisted suicide and 72 per cent of cases of euthanasia. In all other cases, the doctor was present at intervals, or only when called.<sup>557</sup>

### Medical attitudes

Before 1990, empirical evidence did not exist about the practice of euthanasia in the Netherlands, and consequently, evidence about physicians’ opinions was lacking. A survey of Dutch opinions on euthanasia asked physicians whether their opinion on euthanasia had changed over the period of time they had been practising medicine. Sixty-one per cent (61%) said that they had not changed their opinion on euthanasia; 25 per cent said they had become more permissive; and 14 per cent said they had become more restrictive.<sup>558</sup> Fifty per cent of respondents who had become more permissive, and 20 per cent of those who had become more restrictive, explained that their change in opinion had been as the result of their own experiences with dying patients.

Doctors involved in euthanasia report a wide range of emotions, both positive and negative, and sometimes conflicting, as they can occur simultaneously. There has been some research on the effects of assisted dying on physicians, although the manner in which these data are gathered (generally through interviews), means care must be taken in extrapolating the conclusions to the wider medical population.

Of the evidence that does exist, doctors report experiencing a wide range of emotions following their involvement in an assisted death. A 1994 Dutch study found that the range of emotions experienced by doctors who received a request for assisted dying from a patient ranged from extreme shock to anxiety and could lead to sleeplessness and a struggle to come to a final conclusion.<sup>559</sup> However, it also found that doctors could feel a “deep satisfaction” after the act. A 1995 study of Dutch doctors found that 42 per cent experienced feelings of discomfort in assisting in the death of a patient. This was highest in cases of euthanasia, where 75 per cent of those surveyed experienced discomfort. However, willingness to perform euthanasia or assisted suicide again was high, at 95 per cent.<sup>560</sup>



Dutch and American physicians who participated in a qualitative survey of physicians' experiences of assisted dying reported that the emotional burden of performing physician-assisted dying meant that they thought long and hard before agreeing to participate.<sup>561</sup>

### **The doctor-patient relationship**

As is the case elsewhere, there is no formal requirement for a pre-existing doctor-patient relationship in the Dutch law, but cases in which there is no pre-existing patient relationship are closely investigated. There have been some cases where the regional review committees have identified the doctor-patient relationship as being insufficient to allow for proper assessment of the patient's request and suffering. One case in 2005 was reported to the prosecutorial authorities on the grounds of the lack of a sufficiently strong treatment relationship with the patient.<sup>562</sup>

## **7. Reporting and scrutiny**

Dutch law requires every case of euthanasia or assisted suicide to be reported to a regional euthanasia review committee, whose task it is to assess whether the physician has acted in accordance with the law. There are five regional review committees, and each committee is made up of three members: a lawyer (who is also the Chair), a physician, and an ethicist. Data are published annually in Dutch, French and English and can be found at <https://www.euthanasiecommissie.nl/jaarverslagenvoorgaandejaren.asp>.

In 2013, the committees found that physicians had acted in accordance with the law in 99.9 per cent of the total cases reported. In five cases, 0.1 per cent of the total reported cases, the committees found that the physician had not acted in accordance with the law.<sup>563</sup>

In 2012, the End-of-Life Clinic (SLK) was established with the aim of serving patients unable to find a doctor willing to assist them. In 2013, the review committees received 107 notifications from SLK. The regional review committees identified the short handover from attending physician to SLK physician, and the short duration of the SLK doctor-patient relationship, as issues of concern, and decided in 2013 to consider all SLK notifications as non-straightforward cases to be discussed at monthly review meetings.<sup>564</sup>

## **8. Palliative care**

Differing healthcare systems and structures can make it difficult to carry out a comparative study into whether assisted dying impedes or complements the provision or development of palliative care. A study into palliative care development in European countries with euthanasia laws analysed the financing and development of palliative care services; palliative care literature; and attendance at European Association for Palliative Care (EAPC) meetings and concluded that palliative care in the Netherlands, and neighbouring Belgium, had been in continuous development over the past five years – or at least at a similar rate of development as that in surrounding countries, such as Germany and France.<sup>565</sup> The authors of the review concluded that palliative care is well developed in countries with legalised euthanasia or assisted suicide, or at least, it is no less well developed than in surrounding European nations.

A separate study of structural service indicators from the 2005 and 2012 European Atlas of Palliative Care found that the rate of increase of structural palliative care provisions was highest in the Netherlands and Luxembourg, while Belgium remained roughly the same but still ranked amongst the best European countries for palliative care.<sup>566</sup>

Differences that exist in the levels of availability of some resources (e.g., specialist palliative care hospital teams or hospices) may reflect the different models and conceptions of palliative care in these countries. It has also been suggested that the degree of medical specialisation of palliative care may be lower in these countries, as there is a lack of formal certification of palliative medicine as a specialty or sub-specialty, and fewer full time physicians working in palliative care.<sup>567</sup>

A 2006 study investigated the palliative care options available when a patient requested euthanasia, how these were applied, and whether this resulted in a change in the patient's

wishes.<sup>568</sup> In 25 per cent of cases, palliative options were still available. In these cases, the options were applied in 63 per cent of cases, and in 46 per cent of these cases, the patient withdrew their request. The authors noted that where patients declined palliative options, or where the request persisted despite palliative interventions, this was related to the autonomy of the patient, the burden on them, and the medical futility of the option.

Another study identified the involvement of palliative care teams and psychiatrists in the care of a patient as being a factor positively associated with a request for euthanasia, alongside youth; a cancer diagnosis or diagnosis of a disease of the nervous system; and dying at home.<sup>569</sup>

## Part Three: Belgium

### 9. The law

#### Belgian Act on Euthanasia 2002

- The **patient** must be in an intractable medical situation (“*une situation médicale sans issue*”) experiencing “constant and unbearable physical or psychological suffering”, as the result of a severe or incurable injury or disease, which cannot be relieved. They must also have the capacity to make the decision.
- The **request** must be made voluntarily; in writing; and in a “considered and repeated manner”.
- The **doctor** must confirm that the patient is in a constant state of physical or psychological suffering and has repeatedly expressed their desire to end their life; conclude, along with the patient, that there is no other reasonable solution; and consult an **independent doctor** about the serious and incurable nature of the patient’s condition. This independent doctor must review the patient’s medical record, and also examine them.
- Where the doctor believes that death will not occur in the short-term, they must also consult an **additional doctor**, psychiatrist or specialist in the disease concerned, and allow at least one month to pass between the patient’s written application and the euthanasia itself.
- The doctor must submit a form to the Belgian **Federal Control and Evaluation Commission** who will carry out an *ex posteriori* control with regard to compliance with the law.

In February 2014, the Belgian parliament passed legislation which extended euthanasia to competent children of all ages, making Belgium the first country in the world to abolish age restrictions on euthanasia.<sup>570</sup> Based on this expanded law, a request for euthanasia from a minor can be considered, but only if the patient is in a “medically futile condition of unbearable physical suffering” due to an untreatable terminal illness.<sup>571</sup> In these cases involving children under the age of 16, parental consent is required.

### 10. Data

According to the report of the Belgian Federal Committee for the Monitoring and Assessment of Euthanasia, there were a total of 1,807 cases of assisted dying in 2013, up from 1,432 in 2012.<sup>572</sup> This represented 1.5 per cent of all deaths in Belgium, and an average of 150 euthanasia cases a month. Sixty-five per cent (65%) of patients were aged between 40 and 79 and 33 per cent were aged over 79. Previous reports of the Committee noted the high numbers of euthanasia deaths involving middle-aged patients, which they concluded is related to the high frequency of cancer-related deaths in this age group.

Belgium has seen a steady increase in the number of euthanasia cases since the law first came into force. The Federal Committee attributed this to gradual wider dissemination of information on end-of-life-decisions to both patients and doctors.

## 11. Methods and complications

In the vast majority of cases in 2013 (99%), death was achieved by first inducing deep unconsciousness with general anaesthetic, usually by injecting the patient with thiopental, or, more rarely, using other general anaesthetics by direct IV injection. Death can commonly occur spontaneously within a few minutes with thiopental, but if not, an IV injection of a blocking agent causing neuromuscular paralysis is administered. Doctors frequently report that this causes a “calm and quick death” by respiratory arrest within minutes.<sup>573</sup>

The Belgian law only explicitly provides for euthanasia. However, in practice, assisted suicide is permitted by law, providing that the conditions and procedures for euthanasia have been complied with, and the act is conducted under the supervision of a doctor who is present and ready to intervene if necessary. Oral administration of barbiturates was used in just 26 cases (less than 1%) in 2013. In eleven of these cases, death occurred in a few minutes without further action, and in 15 cases, a neuromuscular paralyzing agent was injected after loss of consciousness.

The Federal Committee’s notification form does not include questions about complications associated with the ending of life although there is a section for “any further information the doctor wishes to provide”; no complications or adverse effects were reported through this mechanism in 2013.

## 12. Eligibility

### “Unbearable suffering”

The Federal Committee has held that while there are some factors that can help doctors judge the unbearable nature of suffering, it is largely subjective and depends on the patient’s personality, history and values.

As in the Netherlands, the requirement for the suffering to be “unrelievable” – for there to be no reasonable solution other than assisted death – does not mean that the patient must undergo every possible option available. The patient is entitled to obtain euthanasia after refusing treatment provided the refusal relates to non-curative treatment of the disease or treatment that would have involved particularly serious side-effects.

In some patients (166 cases or 5 per cent of the total performed in 2013), the suffering was not caused by a single disease, but by the co-existence of several diseases. The number of these cases is “markedly” higher than in the 2010-11 period, and is likely to be related to the higher proportion than before of patients over 80-years-old, who may be suffering from a combination of conditions related to the ageing process.

Similarly, in some cases involving patients at a very advanced age, who had multiple incurable diseases, some members of the Federal Committee felt that the suffering and therefore the application for euthanasia were related more to the “natural consequences” of the patients’ age than the diseases they had. Furthermore, some cases examined by the Federal Committee indicated that assessments of the unbearable nature of suffering sometimes took into account suffering linked to the patient’s age, not just the suffering linked to the disease, leading to some differing opinions between the majority of the Committee and some Committee members about the nature of the suffering.

### Physical vs psychological suffering

Cancer was the most commonly cited underlying condition, in 73 per cent of the cases, followed by progressive neuromuscular diseases (6 per cent) and cardiovascular disease (5 per cent).

Belgian law permits euthanasia on the grounds of both physical and psychological suffering. The 2013 report of the Federal Committee noted that in the majority of cases, patients experienced several types of suffering, both physical and psychological: physical suffering was reported in 96.2 per cent of all cases in 2013, and psychological suffering in 72.1 per cent of cases. Physical suffering mentioned included pain; dyspnoea (shortness of

breath); dysphagia (difficulty swallowing); exhaustion; paralysis; and repeated transfusions, amongst others. Psychological suffering included concepts like dependency, despair, and a loss of dignity.

The relatively wide parameters of the law in Belgium have attracted a considerable amount of media attention, and there have been a number of high profile cases involving individuals who have ended their lives in the absence of ‘traditional’ medical suffering, including Nathan Verhelst, a 44-year-old Belgian man who received euthanasia for unbearable psychological suffering after a “botched” sex change operation,<sup>574</sup> and Marc and Eddy Verbessem, 45-year-old deaf twins who received assistance in dying when they discovered they were both going blind.<sup>575</sup> In 2012, 64-year-old Godelieve de Troyer received euthanasia for “untreatable depression”, prompting her son Tom Mortier to challenge the breadth of Belgian law on euthanasia at the European Court of Human Rights.<sup>576</sup> The case is yet to be heard.

Psychological suffering stemming from a mental disorder is a valid basis for euthanasia in Belgium. The Federal Committee does not collect data on how many cases are based on mental disorders, but a study of 100 requests from Belgian patients with psychiatric disorders between 2007 and 2011 found that 48 per cent of requests were granted, and 35 per cent carried out.<sup>577</sup> Of the 13 remaining granted cases, 11 postponed or cancelled the procedure and two committed suicide before the procedure could be carried out. In total six people in the study committed suicide themselves. The study described the modes of suicide as “dramatic”, which the authors felt highlighted the delicate balance of allowing sufficient time for the legal and medical requirements to be met against the need to take action before the suffering reaches an unbearable level and leads to traumatic suicide.

Most patients in the study presented with more than one diagnosis, but the majority (58) suffered from a treatment-resistant mood disorder, such as major depressive disorder or bipolar disorder. Other psychiatric diagnoses included post-traumatic stress disorder (PTSD) (13); schizophrenia and other psychotic disorders (14); and anxiety disorders (11). Seven patients had Asperger’s syndrome, which the researchers said represented a “neglected disease burden”. All of the patients in the study had been referred for psychiatric counselling.

As in the Netherlands, Belgian doctors are far less likely to grant a euthanasia request where the suffering is psychological. In one Belgian study, requests for euthanasia were granted far less often where the suffering involved psychosocial or existential suffering – e.g. being tired of living, or not wanting to be a burden on family – than they were when the suffering was physical – e.g. pain, dyspnoea or vomiting.<sup>578</sup> Furthermore, requests were not granted in any case where a psychiatric disorder was the primary diagnosis. The study was unable to provide information on the reasons why the physicians refused to grant these requests, but they did note other research which indicated that in cases of refused requests, physicians are often not convinced that the suffering is unbearable – particularly where that suffering was psychological, rather than physical.

#### **Death not expected in the short-term**

The Federal Committee interprets death as not being expected in the short-term if it is not expected “in the coming months”. This means that some conditions – mainly progressive neuromuscular disorders or severe multiple paralysis – will require the more intensive process as delineated by the Act, where an additional independent doctor (usually a psychiatrist or specialist in the condition concerned) must be consulted, and a waiting period of one month must be observed.

The Committee notes that euthanasia is “rarely practised” where a disease will not result in death in the near future. In 2013, only 13 per cent of euthanasia cases were performed in patients whose death was not expected in the short-term.<sup>579</sup>

## 13. Request

### Presence of request

Research has found that the request criterion was met in all 2,017 reported cases during the first five years of lawful euthanasia in Belgium.<sup>580</sup>

A Belgian study of 66 life-ending acts without explicit patient request in 2007, found that 24.4 per cent of patients had previously expressed a wish for euthanasia.<sup>581</sup> The same Belgian study found that the main reason for not reporting these cases was that physicians did not view what they were doing as euthanasia. The authors found that in the vast majority of cases (87.9%), physicians labelled their acts in terms of symptom treatment rather than in terms of ending life. The authors assessed the drugs used and found these acts to be similar to intensified pain and symptom treatment and significantly distinct from euthanasia. A separate Belgian study suggested that as many as 92 per cent of unreported cases of “euthanasia” involved life-ending acts, usually involving the use of opioids or sedatives, which physicians did not classify as euthanasia.<sup>582</sup> A more recent study of euthanasia and other end of life practices in the Flanders region of Belgium found that 1.7 per cent of euthanasia cases were “the hastening of death without an explicit request from patients”. The authors of the study did not explore the reasoning behind these cases.<sup>583</sup>

Belgian law also recognises the validity of advance directives requesting assisted dying, provided that the person making the directive had capacity at the time. Such a declaration must be made in writing, in the presence of two adult witnesses, at least one of whom must not have any material interest in that person’s death. The declaration cannot be accepted if it is made or confirmed less than five years before the onset of the patient’s inability to express his will. In 2013, 69 euthanasia cases involved unconscious patients and were performed on the basis of an advance declaration.<sup>584</sup>

### Capacity

In Belgium, the individual seeking assistance must be “legally competent” and the request must be made voluntarily and not as the result of external pressure. Not being fully competent has been shown to have one of the strongest associations with doctors refusing a request for assisted dying.<sup>585</sup>

As in the Netherlands, there is no legal requirement for a psychiatrist to be consulted as part of the course of assisted dying requests, either to assess capacity or to determine the presence of a mental disorder that might affect capacity. In cases where death is not expected in the short-term, however, an additional independent opinion must be sought from either a psychiatrist or a specialist in the disease concerned. In 2013, psychiatrists were consulted as the second independent physician in the overwhelming majority of cases (71%).<sup>586</sup>

There is no evidence from Belgium as to the prevalence of depression in requests for euthanasia.

### Voluntariness

A study of over 900 physicians who reported involvement in requests for euthanasia found that requests were far less likely to be granted for patients aged 80 and over; patients with general deterioration; and patients with depression. The authors concluded that this disproved the repeatedly expressed concern that vulnerable people would receive euthanasia more easily.<sup>587</sup>

## 14. Physicians and the law

### Medical involvement

Belgian law requires the involvement of at least two doctors: “the reporting doctor”, who carries out the request, and a second doctor, “the consulted doctor”. As in the Netherlands, whilst there is a requirement to consult a second doctor, their opinion is not binding.<sup>588</sup>

The Federal Commission notes that doctors “frequently” make use of additional consultations of specialists, in addition to the legal requirement to consult another doctor, which they believe confirms the rigour and seriousness with which doctors act in regard to euthanasia requests.<sup>589</sup>

Similar to SCEN in the Netherlands, Belgium operates the Life End Information Forum (LEIF) which helps doctors access specifically trained independent physicians for consultation, and to also provide information and support for patients and caregivers about end-of-life choices, including palliative care. However, doctors are not compelled to consult LEIF doctors when seeking a second independent assessment.

### Medical attitudes

Although there is little evidence of the attitudes of Belgian doctors to euthanasia prior to the legislation being passed, there is significant evidence to suggest that the law has the support of Belgian physicians. A 2009 study into the attitudes of physicians found that the overwhelming majority (90.4%) agreed or strongly agreed that the administration of life-ending drugs at the explicit request of a patient is acceptable for patients with a terminal disease with extreme uncontrollable pain or other uncontrollable suffering.<sup>590</sup> Compared to a survey conducted in 2002, shortly after the law was passed, where the acceptance of euthanasia amongst physicians stood at around 78 per cent, this represents an increase in physician acceptance of euthanasia. The authors suggest that legalisation, the apparent lack of cases of abuse, and an increased acceptance of euthanasia amongst the public may have contributed to this acceptance.

Just 18.6 per cent said they were under no circumstances prepared to administer drugs to hasten death at the explicit request of a patient. The study found that the holding of religious views was strongly related to unwillingness to perform euthanasia. However, the authors do note the 34 per cent response rate to the survey, which limits the ability to extrapolate the results more generally.

### The doctor-patient relationship

As in other jurisdictions where assisted dying is permitted, there is no requirement for a certain nature or length of doctor-patient relationship. However, the Belgian Act on Euthanasia states that the physician must ascertain the patient’s nature of suffering and desire for euthanasia through consulting the patient “several times at intervals that are reasonable with regard to developments in the patient’s condition”.<sup>591</sup> This indicates that, even if there is no pre-existing relationship when the patient first expresses their desire for euthanasia, one will develop over the course of consultations.

## 15. Reporting and scrutiny

Under the Belgian Act on Euthanasia, the medical practitioner must submit a form to the Federal Control and Evaluation Committee, made up of 16 members who are appointed on the basis of their knowledge and experience, and are medical practitioners and legal experts. The Committee carries out an *ex posteriori* control with regard to compliance with the law. Should the Commission feel the law has not been complied with, the case is referred to the public prosecutor.

In 2013, 86 per cent of cases were accepted immediately. The committee opened the remaining 14 per cent of cases and found that most of the points at issue concerned missing administrative information or procedural details. The answers provided each time gave useful information and the declarations could be approved. Given that none of the declarations included any elements raising doubts about compliance with the “essential elements” of the law, no cases were referred to the courts.

Data are collected and published annually in French and Dutch by the Federal Control and Evaluation Committee. The latest report can be found at <http://www.health.fgov.be/eportal/Healthcare/Consultativebodies/Commissions/Euthanasia/Publications/index.htm#.Vgv3ZflViko>.

## 16. Palliative care

The development of the law on assisted dying in Belgium has been broadly characterised by a lack of acrimony between the palliative care movement and the proponents of assisted dying.<sup>592</sup> Euthanasia is perceived as part of the palliative care continuum, as formally expressed in a position statement from the Federation of Palliative Care Flanders.<sup>593</sup> This is largely due to the fact that in Belgium, new legislation regarding patients' rights and palliative care was implemented in 2002 at the same time as the euthanasia legislation. (A similar law was passed in Luxembourg at the same time as the law on euthanasia). This legislation doubled public funding for palliative care; stated that every patient has a right to palliative care; and set out measures for every hospital in Belgium to have a palliative care team. Shortly after legalisation, the Belgian Medical Disciplinary Board issued joint guidelines for euthanasia and palliative care. The guidelines broadly endorsed the law and emphasised the recourse to palliative care before carrying out euthanasia – which is further enforced by the fact that all LEIF doctors are trained in palliative care. Some studies have indicated that throughout the development of the legalisation of euthanasia and beyond, doctors entered into end-of-life decision discussions more frequently.<sup>594</sup> A recent survey of euthanasia and end-of-life practices in the Flanders region of Belgium indicated that palliative care services were involved in 73.7 per cent of all euthanasia cases.<sup>595</sup>

As in the Netherlands, a study into palliative care development in European countries with euthanasia laws analysed the financing and development of palliative care services; palliative care literature; and attendance at European Association for Palliative Care (EAPC) meetings and concluded that palliative care in Belgium had been in continuous development over the past five years – or at least at a similar rate of development to that in surrounding countries, such as Germany and France.<sup>596</sup>

A separate study of structural service indicators from the 2005 and 2012 European Atlas of Palliative Care found that the rate of increase of structural palliative care provisions was highest in the Netherlands and Luxembourg, while Belgium remained roughly the same but still ranked amongst the best European countries for palliative care.<sup>597</sup> However, the same study also noted that the effects of legal physician-assisted dying may still manifest themselves in the longer term, and that further research should investigate whether patients seek assisted dying due to a lack of sufficient palliative care. The authors concluded that if nations are considering physician-assisted dying, palliative care services must be enhanced at the same time – as was the case when Belgium legislated on euthanasia.

A study into physicians' attitudes towards euthanasia found that palliative care doctors were less likely to perceive the euthanasia law as having a negative effect on the development of palliative care, and were in fact more likely to have performed euthanasia than other physicians with less experience of care for the dying. The authors conclude that most physicians in the study support the view that ending the life of a patient at their request can be part of good palliative care.<sup>598</sup>

**Part Four: Oregon**  
**17. The law**

**Death with Dignity Act 1994**

- The **patient** must be at least 18 years old, a resident of Oregon, and have a terminal illness that will cause their death within six months. They must also have capacity.
- The **request** must be made by the patient, orally in the first instance, and then in writing at least 15 days after the original request. It must be signed by two independent witnesses, who confirm that the patient is competent and acting voluntarily.
- The **physician** must confirm that the patient meets the eligibility criteria; ensure that they are informed of all other palliative and treatment options; and refer the patient for counselling if they believe them to be suffering from a psychiatric or psychological disorder causing impaired judgement.
- A second **independent physician** must confirm the patient’s diagnosis and make a determination that the patient is competent and acting voluntarily.
- Doctors must inform the **Oregon Department of Health** of any lethal prescription they write.

**18. Data**

In 2014 in Oregon, there were a total of 34,160 deaths.<sup>599</sup> In the same year, 155 people received life-ending prescriptions, of which 94 (60.6%) ingested and died from the medication. Eleven (11) patients with prescriptions written during 2012 and 2013 died after ingesting the medication in 2014, bringing the total deaths to 105.<sup>600</sup> Thirty-seven (37) of the 155 patients who received a lethal prescription in 2014 did not take the prescription and subsequently died of other causes. No information is available about the remaining 24 cases. Since the Act came into force in 1998, a total of 859 individuals have died with assistance (Figure 5, below). Between 1998 and 2012, assisted suicides under the Death with Dignity Act represented approximately two in every 1,000 deaths;<sup>601</sup> in 2014, assisted deaths represented around three in every 1,000 deaths.<sup>602</sup>

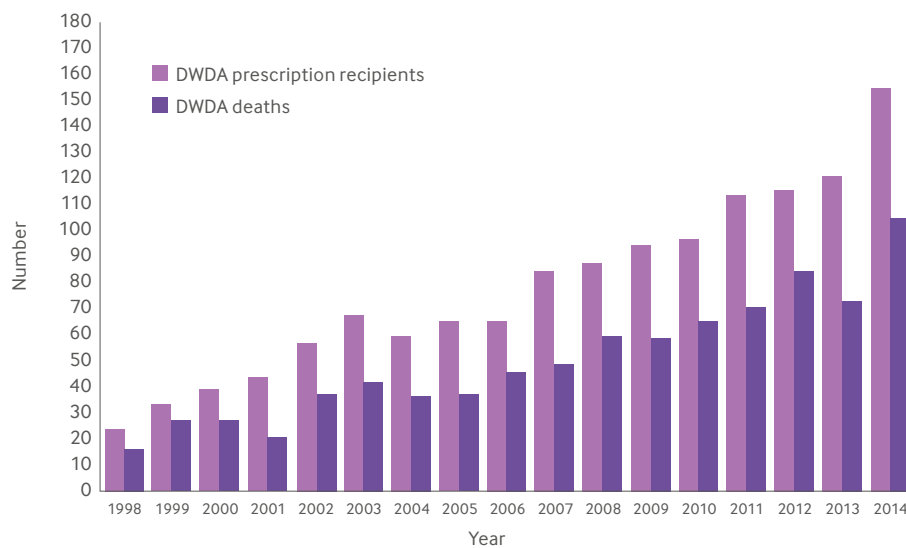


Figure 5 – Death with Dignity Act prescription recipients by year. Taken from Oregon Public Health Division (2015) Oregon’s Death with Dignity Act: Annual Report 2014. Department of Health: Oregon.



The discrepancy between the number of recipients of lethal prescriptions and the numbers of deaths has led some to conclude that knowing the option is there for them has the effect of reassuring many terminally ill patients. One study further noted that only a small percentage of those who state an interest in physician-assisted suicide will actually express this to a doctor and make a clear request. Although 17 per cent of respondents said the decedent had personally considered seeking assistance in dying, only 1-2 per cent formally requested it.<sup>603</sup>

A study into the number of suicides in Oregon since the legislation was passed found that there was an increase in the total number of suicides, including assisted suicides. The introduction of physician-assisted suicide was not associated with a reduction in non-assisted suicide rates.<sup>604</sup>

## 19. Methods and complications

Oregon's Death with Dignity Act 1994 permits individuals who meet the eligibility criteria to "request and obtain a prescription" which will enable them to end their life. The accompanying FAQs to the Act make it clear that it is a matter of clinical discretion what that prescription might be, but that to date, most patients who have died under the Act have received a prescription for an oral dosage of a barbiturate.<sup>605</sup> In 2014, 60 per cent of all individuals who died with assistance ingested secobarbital, and 39 per cent ingested pentobarbital.<sup>606</sup> There is no formal guidance under the Act as to the circumstances in which the medication should be taken, although the statute specifies that the doctor must "counsel the patient about the importance of having another person present when [they] take the medication... and of not taking the medication in a public place".<sup>607</sup>

Out of the total of 859 cases of assisted death since the Death with Dignity Act came into force, there have been 507 cases with zero complications.<sup>608</sup> However, due to reporting mechanisms, it is "unknown" whether there were any complications in 329 of the cases. This is largely due to a change in reporting procedures in 2010, whereby information about the circumstances of the death are only accepted when the physician or healthcare professional was present at the time of death. As a result, in 2014, data are only available for 20 out of the 105 cases. From the data that are available (1998-2014), individuals regurgitated medication in 22 cases and one individual had a seizure. Six patients regained consciousness after ingesting the medication.<sup>609</sup> The information included in the annual reports from Oregon states that the majority of these patients died from their underlying condition days later, but in one case, the individual lived for another three months before dying from the underlying condition. One patient remained in a minimally conscious state until dying six days later.<sup>610</sup>

Information on the time from taking medication to death is available in 512 of the total deaths under Oregon's Death with Dignity Act. Of those cases, half died within 25 minutes (the shortest time being one minute) and half took longer than 25 minutes (the longest being 104 hours). In 2014, the median time between ingestion and death was 27 minutes.<sup>611</sup>

## 20. Eligibility

In Oregon in 2014, cancer was the most common condition for which people sought assistance in dying (68.6%), followed by amyotrophic lateral sclerosis, or ALS (16.2%) and chronic lower respiratory disease (3.8%).<sup>612</sup>

In one study, 38 per cent of Oregon physicians eligible and willing to write prescriptions under the Death with Dignity Act were not confident in their ability to determine that an individual was expected to die within six months.<sup>613</sup> A separate survey of Oregon physicians, shortly before the legislation came into force, found that half were not confident that they could predict, with accuracy, that a patient had less than six months to live.<sup>614</sup>

## 21. Request

### Presence of request

The law in Oregon requires the patient to make a request for assisted suicide orally, in the first instance, and then in writing at least 15 days after the initial request. It must be signed by two independent witnesses, at least one of whom is not a relative, or employed by the healthcare facility caring for the patient, who confirm that the patient is competent and acting voluntarily.

Data gathered in Oregon for the 673 prescriptions that resulted in death between 1998 and 2012 indicate that a request was present in all reported cases, since the mandatory waiting period of 15 days between the first oral request and death was respected for all patients.<sup>615</sup>

The data from Oregon since the law first came into force show a range of between 15 and 1,009 days duration between the first request and death, with a median of 47 days.<sup>616</sup>

### Capacity

The Death with Dignity Act requires the individual to be “capable” of making the decision, meaning that in the opinion of a medical professional, the individual has the ability to make and communicate health care decisions to health care providers.

It has been suggested that physicians’ ethical views on assisted dying may influence assessments of capacity, in that those who are more opposed to assisted dying may apply a higher threshold for competence than those who are more supportive.<sup>617</sup>

### Depression

A 2000 study of Oregon physicians found that 20 per cent of patients who had requested assisted suicide had symptoms of depression, but that none had received a lethal prescription.<sup>618</sup> A more recent study which compared Oregonians pursuing assisted dying with a similar group who did not have an interest in it, found that those requesting assistance in dying had higher levels of depression and hopelessness.<sup>619</sup>

Another study on the prevalence of depression in 58 Oregonians, who had either requested aid in dying from a physician, or contacted an aid in dying advocacy organisation, urges caution.<sup>620</sup> It found that one in four of those patients had depression. Twenty-two individuals did not receive a prescription. Of the 18 patients who did receive a prescription, three had been suffering from depression, and these three died by ingesting the lethal drugs. The authors noted that whilst the majority of terminally ill Oregonians who receive assistance in dying will not have a depressive disorder, the current practice of the Death with Dignity Act may fail to protect some patients whose choices are influenced by depression from receiving a prescription for a lethal drug. They suggested that “increased vigilance and systematic examination” for depression amongst patients seeking aid in dying should be explored.

Although every country which permits assisted dying insists on the presence of capacity, no country has a policy of mandatory psychiatric review for assisted dying requests. A review of all assisted dying legislation suggested that the absence of a mandatory psychiatric role was concerning, as it meant that reversible psychopathology could be missed, and a patient’s decision to end their life may be more informed by treatable mental disorders rather than life-long preferences.<sup>621</sup> The same study noted that whilst national review and control committees included medical members, none require the membership of a psychiatrist.

Oregon, however, requires physicians to refer individuals for counselling if they suspect the individual has a mental illness or disorder that is causing impaired judgement.<sup>622</sup> Since the Act first came into force, 5.5% of individuals who have died have been referred for psychiatric evaluation,<sup>623</sup> and the proportion of referrals for psychiatric evaluation has fallen year on year. It is unknown how many people seeking assistance who are then referred for psychiatric evaluation do not receive a lethal prescription. The efficacy of psychological assessment has been questioned elsewhere. The Rights of the Terminally Ill Act which briefly legalised euthanasia in Australia’s Northern Territory in 1996 included a provision for mandatory psychological assessment. Only a very small number of cases of euthanasia

occurred before the law was repealed, but questions have been raised about whether this requirement was effective in picking up psychiatric disorders, and whether patients were fully honest in their psychiatric assessments.<sup>624</sup>

Additionally, physicians are not always confident in their abilities to identify depression in patients seeking assisted suicide. A study of Oregon physicians shortly before the Death with Dignity Act came into force found that 28 per cent were not sure they could recognise symptoms of depression in patients seeking lethal prescriptions.<sup>625</sup> (However, by 2001, 69 per cent of physicians eligible to prescribe under the Act reported making efforts to improve their recognition of psychiatric disorders.)<sup>626</sup> Psychiatrists surveyed in Oregon around the same time (1996) were generally more confident in their ability to assess capacity, with 95 per cent of them confident or very confident that they could determine whether a mental disorder was influencing the decision for assisted suicide, in the context of a long-term relationship with a patient.<sup>627</sup> However, the percentage who were very confident shrank to just 6 per cent in the context of a one-off, single evaluation.

### **Voluntariness**

Some light may be shed on the issue of coercion in assisted dying decisions by exploring some of the reasons why people choose an assisted death. In Oregon in 2014, the three most frequently mentioned end of life concerns were loss of autonomy (91.4%); decreasing ability to participate in activities that make life enjoyable (86.7%); and loss of dignity (71.4%). These have consistently appeared in the top three end of life concerns since the law first came into force in 1998.<sup>628</sup> However, significant numbers also cited concerns about being a burden on their family, friends and caregivers (40%) or the financial implications of medical treatment (4.8%), suggesting that there can be more subtle forces at play affecting patients' decisions.

Various studies have indicated that there is no evidence of heightened risk of assisted dying for vulnerable people – e.g. the elderly, persons with low educational status and black and minority ethnic groups. Since the law came into force, the overwhelming majority of Death with Dignity recipients have been white (97.1%), and a significant number (72.1%) have at least some college level education.<sup>629</sup> A 2007 study analysed data from Oregon and the Netherlands and concluded that the majority of those who receive physician assistance in dying enjoy comparative social, economic, educational and professional privileges, and that there is no evidence for the claim that assisted dying has a disproportionate impact on patients in vulnerable groups.<sup>630</sup>

However, other commentators have criticised this study for focussing on an overly narrow socio-economic conception of vulnerability, which overlooks emotional and personal vulnerability.<sup>631</sup> They point to evidence from the annual Oregon statistics which indicate that the highest resort to physician-assisted suicide is amongst the elderly, which they define as being 65 and older – the 2007 study only examined the evidence relating to individuals over the age of 85, omitting data on those aged between 64 and 85. They further note, that in qualitative research vulnerability in end-of-life decision making has been shown to be more related to communicative difficulties, situation specific issues, having unrelieved symptoms or distressing medical conditions, or being socially undervalued – all factors which transcend traditional socio-economic classifications of vulnerability.

## **22. Physicians and the law**

### **Medical involvement**

The law in Oregon requires the involvement of two doctors, who must confirm that the patient meets the eligibility criteria and that they are competent and acting voluntarily. The law does not require the presence of a physician when a patient takes the lethal substance. Data gathered by the Oregon Public Health Division indicates that the individual's ingestion of the medication is in some circumstances supervised by the prescribing doctor; in other circumstances by another healthcare provider; and in some cases by no provider at all. In 2014, the prescribing physician was present in 14 cases; another provider was present in 6 cases; and there was either no provider or the circumstances were unknown in 85 cases.<sup>632</sup> Medical involvement at the moment of death (not just the point of ingestion) seems to be declining, with there being no provider present in 80.2 per cent of all cases in

2014, compared to 44.9 per cent from 1998 to 2013. An Oregon doctor who gave evidence to the 2010 Commission on Assisted Dying explained that there was always a doctor on call during an assisted death in case of possible complications.<sup>633</sup>

### Medical attitudes

A 2001 study of Oregon physicians eligible to prescribe under the Death with Dignity Act found that 51 per cent of respondents supported the Act; 31 per cent opposed it; and 17 per cent had no view.<sup>634</sup> Four out of five claimed their views on assisted dying had not changed since the law was enacted – but out of those who had changed their view, almost twice as many reported that they had become more supportive (13%) than more opposed (7%). In 1998, the first year of Oregon's Death with Dignity Act, fourteen physicians wrote lethal prescriptions for fifteen patients. The annual report from the Oregon Department of Health noted that for some of these physicians, the process of participating in physician-assisted suicide had a great emotional impact, with some describing it as "excruciating" and as "making [me] rethink life's priorities."<sup>635</sup> The same data regarding emotional impact on participating physicians have not been gathered for subsequent annual reports. Other later studies indicate similar conclusions, finding that participation in assisted suicide required a large investment of time and was emotionally intense.<sup>636</sup> However, they also found that, whether they prescribed or not, doctors rarely regretted their decisions.

Despite legalisation, doctors report concerns about being ostracised by their colleagues, or about participation having a negative impact on their professional practice. Fifty-eight percent (58%) of doctors eligible to write lethal prescriptions under the Death with Dignity Act were "at least a little concerned" about being labelled a "Kervorkian" (a reference to American doctor Dr Jack Kervorkian, who was convicted of murder for his involvement in euthanasia practices, and widely labelled in the press as "Dr Death").<sup>637</sup> A separate survey of Oregon physicians who supported assisted dying found that they still had a number of practical concerns about assisting in a patient's death, mostly in relation to their professional practice. Over half (53%) were concerned that a patient's family might sue, and 51 per cent were concerned about the consequences of a failed attempt. Some respondents were worried that writing a prescription might jeopardise their licence to practise elsewhere in the US (23%); lead to sanctions from employers (24%); or ostracism from colleagues (25%).<sup>638</sup>

### The doctor-patient relationship

The average duration of the doctor-patient relationship in deaths under the Oregon Act is 13 weeks, with a full range from between zero and 1,905 weeks.<sup>639</sup>

Respondents to a qualitative survey of American and Dutch doctors found that a strong doctor-patient relationship could facilitate the occurrence of physician-assisted dying discussions and that, in turn, these discussions could strengthen the doctor-patient relationship, as the conversations were intense and very revealing of patients' values and goals.<sup>640</sup> It is important to note the inclusion of the word "discussion" here – subsequent studies have suggested that the quality of the doctor-patient relationship does not necessarily rest on the willingness of a physician to provide a lethal prescription, but on their willingness to just discuss the matter. Ganzini found that following the enactment of the Death with Dignity Act, a much larger proportion of physicians discussed assisted suicide with their patients, and that physicians perceived that more patients found these conversations useful than upsetting.<sup>641</sup> A survey of patients and family members showed that most patients felt comforted by being able to talk about dying, and that the openness of the clinician to discuss this issue led to the patient feeling more comfortable about discussing other worries, concerns, and vulnerabilities regarding their illness – which, the authors concluded, is often more important to the patient than receiving a lethal prescription.<sup>642</sup>

Where requests are discussed and then refused, there is the potential for the doctor-patient relationship to be affected. A survey of American and Dutch doctors found that refusing a request for physician-assisted dying could negatively impact on the doctor-patient relationship – and that even though it would not necessarily end it, it would leave the relationship "strained".<sup>643</sup> A 2001 study of Oregon doctors eligible to prescribe under the

Death with Dignity Act found that breakdowns or ruptures of the doctor-patient relationship were more likely to occur if the physician opposed assisted suicide: many more physicians who opposed the Act reported that a patient was concerned or upset, or left the physician's practice because of the physician's views on assisted suicide, compared with physicians who supported the Act.<sup>644</sup>

Respondents to a survey of American and Dutch doctors said that the topic of assisted suicide was generally initiated by patients. However, some physicians felt comfortable initiating discussions about physician-assisted dying because they realised that patients had heard of it, and felt an obligation to ensure patients understood how this fitted into possible treatment options.<sup>645</sup>

Around a third of physicians in Oregon have indicated a willingness to prescribe lethal substances under the Death with Dignity Act.<sup>646</sup> This leads to a situation in which patients seeking assisted dying, but unable to obtain it from their regular doctors seek or are directed to other physicians who are willing to consider their request, but have no prior knowledge of them as patients. It has been reported, however, that some doctors are contractually prohibited from participating in assisted dying at their place of employment.<sup>647</sup>

### 23. Reporting and scrutiny

Doctors must inform the Oregon Department of Health of any lethal prescription they write. The Department of Health does not, however, perform a regulatory function or scrutinise decisions. It is their responsibility to report any irregularities or concerns to the Oregon Board of Medical Examiners.<sup>648</sup> During 2014, no referrals were made to the Oregon Medical Board for failure to comply with the law.

The Oregon Department of Health publishes annual reports on the operation of the Death with Dignity Act, which can be found at <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct>.

### 24. Palliative care

As is the case in much of the rest of the world, there is some evidence to suggest that palliative care in Oregon has improved in recent years. A 2001 study of Oregon physicians found that 35 per cent of all deaths in Oregon in 1999 occurred in hospices, up from 22 per cent in 1994.<sup>649</sup> Whilst the perception amongst respondents was that hospice care had become more readily available, the authors of the study in fact suggested that it was physician awareness of services that had improved. Various studies carried out by Linda Ganzini have found that many physicians have made a conscious effort to improve their knowledge of palliative care, and that their attitudes to and care of dying patients had improved following enactment of the Death with Dignity legislation: 30 per cent reported referring more patients to hospice care, and 76 per cent reported that they had made efforts to improve their knowledge of pain management in the terminally ill.<sup>650</sup> Ganzini further found no evidence to suggest that doctors were using assisted suicide in lieu of palliative care, and that as a result of palliative interventions, some patients, although not all, changed their mind about assisted suicide.<sup>651</sup>

In 2014 in Oregon, 93 per cent of patients who died under the Death with Dignity Act were enrolled in hospice care, either at the time the lethal prescription was written, or at the time of death.<sup>652</sup> As noted above, the nature and provision of palliative care differs between countries, and hospice care may be provided on a different model. Some authors, however, have suggested that the high number of individuals in hospice care who choose assistance in dying indicates that inadequate palliative care is not a significant motivation for seeking assistance in dying.<sup>653</sup> One author concluded that "patients are electing to hasten their deaths not because they are receiving inadequate care, but because the care they receive cannot remedy their anxiety, frustration, hopelessness, and anguish."<sup>654</sup>

## Part Five: Switzerland

### 25. The law

#### Article 115 of Swiss Criminal Code 1942

- Assisted suicide is permitted as long as the motive for doing so is not selfish.
- The development of the law has made clear that the person requesting assistance must have capacity.
- The Swiss Academy of Medical Sciences (SAMS) guidance states that participating in assisted suicide is a matter of individual conscience, and that physicians may assist in the suicide of a patient who is approaching the end of life, providing that the person has capacity and has made a voluntary, persistent, and well-considered request and this has been checked by another person (not necessarily a physician).<sup>655</sup>
- A marked feature of the situation in Switzerland is that assisted suicide is organised by a number of “right-to-die” societies, such as EXIT or Dignitas.

### 26. Data

Switzerland does not regularly publish official statistics on assisted dying, as assisted suicides are not differentiated from suicide in official records: both must be reported as “unnatural deaths” to the local authorities, which police and medical officers are then required to investigate. The Swiss government has produced only one official report of the practice in 2012, which analysed assisted suicide and suicide cases from 2009. In 2009, just under 300 cases of assisted suicide were registered in Switzerland, which represented 4.8 per 1000 deaths.<sup>656</sup> There has been a steady increase in the numbers of assisted suicides, up from just under 50 in 1998, the year figures were first gathered. Whereas in the early years, slightly more men than women resorted to assisted suicide, since 2001 considerably more women have done so. Ninety per cent (90%) are aged 55 or over.

Another retrospective analysis of all case files of assisted suicide kept by one of Switzerland’s right to die organisations over a ten year period between 1990 and 2000 found that the organisation assisted in 748 suicides amongst Swiss residents, 0.1 per cent of total deaths.<sup>657</sup> Over the ten year period of the study, the number of assisted deaths nearly quadrupled from 100 in the first three years studied to 389 in the last three.

### 27. Methods and complications

Swiss law does not dictate how assisted suicide should be performed. However, in practice almost all cases involve the prescription of the barbiturate sodium pentobarbital, which is administered orally.

A brochure for one right-to-die organisation explains that individuals wishing to end their lives will ingest a fatal dose of sodium pentobarbital, normally administered in a glass of water. This is usually preceded by an anti-emetic, intended to prevent vomiting. The brochure notes that as sodium pentobarbital is alkaline and “does not taste pleasant”, many individuals choose to eat or drink something sugary immediately afterwards. Individuals who cannot swallow and who are fed via a gastric tube will administer the drug themselves through the tube. Individuals who can neither swallow nor handle a gastric tube may administer the sodium pentobarbital intravenously.

There has also been some experimentation with the use of oxygen deprivation by helium via a facemask in a number of cases. A review of four cases of this method found a wide variation in the time to unconsciousness and death, which was attributed to a poorly fitting face mask which did not create an environment of complete oxygen deprivation.<sup>658</sup> Some commentators have noted that since helium is not subject to regulatory restriction in the same way that barbiturates are, it effectively removes the procedural safeguard of ensuring that assisted suicides are subject to accepted medical practice.<sup>659</sup>

In the absence of official statistics on the issue it is not possible to provide comprehensive data on complications. Nevertheless, there were “no serious complications or cases of reawakening from coma” reported at one right-to-die organisation in a ten year period.<sup>660</sup> The median interval between unconsciousness and death following oral administration of sodium pentobarbital, amongst the 300 cases in Canton Zurich, was 23 minutes, with a range between 7 minutes and 18 hours.

## 28. Eligibility

### Underlying condition

In Switzerland, assisted suicide in the absence of a selfish motive is in principle legal, regardless of the condition of the person seeking it. However, the law only permits physicians to prescribe barbiturates within the limits of accepted professional practice – which, as outlined by the Swiss Academy of Medical Sciences, is when the individual has a disease which justifies the assumption he is “approaching the end of life”.<sup>661</sup>

In the review of assisted suicide deaths using data from 2009, cancer was reported as the underlying disease in 44 per cent of cases, with neurological conditions (19%) and cardiovascular diseases (9%) coming second and third. Depression was reported as the underlying cause in 3 per cent of cases, and dementia in 0.3 per cent.<sup>662</sup>

Swiss law has also indicated that the prescribing of life ending medication may also be legitimate in the case of a serious, incurable, and longstanding mental disorder, which leads an individual “no longer to consider his life worth living.”<sup>663</sup> However, individuals with mental disorders requesting assisted suicide will have to undergo extensive psychiatric evaluation, in order to demonstrate that they have capacity, and that their request is not the product of their mental disorder.<sup>664</sup> A recent ruling from the European Court of Human Rights found that Switzerland’s absence of clear regulations on the circumstances in which individuals who are not suffering from a terminal illness may be able to end their lives with assistance violates the right to private life under Article 8 of the ECHR. It further noted, however, that it is up to the domestic authorities to issue such guidance, and the Court could not take a view on the substantive content of such guidelines.<sup>665</sup> At the time of writing, no guidelines have yet been published.

There is evidence of different conceptions of “suffering” between doctors and patients, which emphasises the importance for good communication in the doctor-patient relationship. Physicians have a tendency to focus more on physical suffering, such as pain and chronic fatigue, whereas patients felt that it was not so much physical pain which made their lives unbearable, but more intangible suffering, such as fear of dependence, not being able to participate in normal daily life, or mental suffering, due to deterioration.<sup>666</sup> Evidence from assisted deaths in Switzerland also shows that concerns relating to autonomy are more often noted by patients seeking assistance than by physicians.<sup>667</sup> However, the same study found that over half (58%) of patients requesting assistance in suicide cited pain as their reason. The authors suggest that the difference in results may be due to the fact that Swiss law and regulation require physicians participating in assisted suicide to assess the medical condition motivating a person to seek assistance in dying, leading them to focus more on medical reasons rather than existential ones in their reporting. A separate study of Swiss doctors suggested that many physicians have difficulty addressing the existential suffering of patients, as this is seen as falling outwith the traditional scope of medicine.<sup>668</sup>

### “Suicide tourism”

Since the 1980s, many organisations have formed to facilitate assisted suicide. There are five assisted suicide organisations in Switzerland, with the most well-known being Exit (which only assists Swiss residents) and Dignitas (which mainly assists individuals from abroad). The option of ending one’s life with few restrictions has attracted many people to travel to Switzerland to end their lives in a practice that has become known as “suicide tourism”.

A recent study found that “suicide tourism” has increased year on year: 123 foreign citizens travelled to Switzerland to die in 2008 increasing to 172 in 2012.<sup>669</sup> The same study found that British citizens formed the second largest group of foreign citizens ending their life

in Switzerland, second only to Germany. There have been a number of high profile cases of “suicide tourism” which have attracted much media attention in the UK, including Sir Edward Downes, who had become almost blind and suffered from loss of hearing, and who travelled to Switzerland to die alongside his wife Joan who had cancer;<sup>670</sup> Daniel James, a 23-year-old rugby player paralysed in a training accident;<sup>671</sup> and Nan Maitland, an 84-year-old woman who suffered from arthritis.<sup>672</sup> Most recently, Jeffrey Spector, who had an inoperable spinal tumour but who was not terminally ill, elected to travel to Switzerland before his disease progressed to a point where he could not take his own life.<sup>673</sup> In August 2015, British newspapers reported that 75-year-old former nurse Gill Pharaoh, who “had no serious health problems”, ended her life in Switzerland.<sup>674</sup> In an interview with *The Sunday Times* before her death she stated that her experience as a nurse had shown her that the reality of old age was “awful” and she did not want to live to become a “hobbling old lady”.<sup>675</sup> Shortly afterwards, newspapers reported on the case of Bob Cole, who had mesothelioma, and who had travelled to Dignitas to end his life.<sup>676</sup> He had travelled to Dignitas 18 months previously to assist his wife Ann, who had supranuclear palsy, a degenerative brain condition, to end her life.

## 29. Request

### Capacity

There is no formal process for requesting assistance in dying. However, the Swiss Academy of Medical Sciences states that in order for a physician to assist in the death of a patient, that person must have capacity and have made a voluntary, persistent, and well-considered request. Capacity is assessed according to the test set out in the Swiss Civil Code, although it has also been reported that individual right-to-die organisations have also developed their own tests.<sup>677</sup>

There have been cases of prosecution where an individual has been prescribed a lethal substance where there were doubts about their capacity.<sup>678</sup> However, these cases involved individuals with mental disorders and physicians who did not act with due care. It is therefore not known how many individuals not suffering from a mental disorder are refused assistance on the basis of a lack of capacity.

It is not known whether, where there are doubts about capacity, individuals are systematically referred to a mental health professional for further evaluation, or to detect the presence of a mental disorder.

### Depression

There is little evidence regarding the prevalence of depression in requests for assisted suicide in Switzerland and the evidence that does exist has been described as “low quality”.<sup>679</sup> The authors of this study noted the results of one survey which found that 27 per cent of people whose request was granted by one right-to-die organisation were defined as depressed, and at least 2 per cent of people using the same right-to-die organisation at a different time were found to have a diagnosis of depression in the records of public psychiatric institutions. The authors indicated that this may be a cause of concern over the informality of the way that Switzerland regulates physician-assisted suicide, and the involvement of lay people in the assessment process.

### Vulnerability

One Swiss study of over 1,000 assisted suicides across a five year period found that although assisted suicide was associated with people with higher educational attainment and higher socio-economic status, it was also more likely amongst women and amongst groups with particular vulnerabilities, such as those who live alone, and perhaps experiencing social isolation and loneliness.<sup>680</sup>



### 30. Physicians and the law

#### Medical involvement

Swiss law does not explicitly provide for a role for doctors. As long as there is no selfish motive, any individual may in principle assist in the suicide of another. However, if an individual wishes to end their life using a lethal substance, medical professionals are essentially gatekeepers to the process. As noted above, only physicians can administer, dispense or prescribe lethal substances, commonly sodium phenobarbitone, and only within the limits of accepted professional and scientific practice.<sup>681</sup>

These parameters for assistance have been adopted by the Swiss Academy of Medical Sciences (SAMS) which states, in guidance issued in 2004 and updated in 2013, that physicians may assist in the suicide of a patient who is approaching the end of life, as a matter of individual conscience, providing that the patient has capacity, and makes a voluntary, persistent, and well-considered request.<sup>682</sup> The physician must also explore all other options with the patient. Prior to 2004, the Academy took the position that assisted suicide was not part of medical practice.<sup>683</sup>

Swiss right-to-die organisations follow individual processes to determine whether an individual meets the criteria for assistance. Once this initial process has been completed, a physician (usually the individual's own GP) must be contacted to independently verify that a person meets that criteria. Since 2008, physicians in Zurich have been required to meet the individual seeking assistance on at least two occasions to verify whether that individual meets the criteria.<sup>684</sup>

#### Medical attitudes

A random sample of 4,800 Swiss physicians in 2014 found that the vast majority (77%) of the 1,318 respondents thought that assisted suicide was justifiable in principle, while 22 per cent were fundamentally opposed to it.<sup>685</sup> Less than half (43%) were personally prepared to carry it out, while just over a quarter (28%) "tolerated" physician-assisted suicide, but would not participate themselves. The study also found that support for assisted suicide depended on the specific situation, and that there was greater acceptance the more clearly a purely physical and terminal disease was present. The authors found that a total of 78 per cent agreed that physician-assisted suicide was justifiable where a patient was seriously ill, suffering severe pain and approaching the end of life, with 58 per cent answering "yes" and 20 per cent answering "probably." Support for assisted suicide fell in hypothetical cases involving patients who were not physically or terminally ill: 32 per cent agreed that assisted suicide was justifiable where the patient had a severe and chronic mental illness (10 per cent saying yes and 22 per cent saying probably); 29 per cent agreed that it was justifiable in cases of dementia (10 per cent saying yes and 19 per cent saying probably); and 48 per cent agreed in cases of elderly patients with co-morbidities dependent on care (21 per cent saying yes and 27 per cent saying probably).

#### The doctor-patient relationship

As is the case in other jurisdictions permitting assisted dying, there is no formal requirement for a doctor-patient relationship of particular length or quality. However, in Switzerland it has been reported that up to a third of patients receive a lethal prescription from a physician affiliated with a right-to-die organisation, with whom they have no pre-existing relationship, rather than their own doctor.<sup>686</sup>

A Swiss study of relatives' experiences of having family members die with assistance found that several relatives perceived health care professionals to be uncomfortable in addressing existential and moral issues, and that as a result, patients were reluctant to discuss their personal beliefs concerning reasons for assisted suicide with them. Relatives felt that some doctors had difficulty in rationalising their own personal beliefs sufficiently well to enable an open discussion, which, the authors suggested, may explain the perceived barriers in communication.<sup>687</sup>

### 31. Reporting and scrutiny

There is no central regulatory body. Cantonal health regulations require healthcare workers to notify the police of all unnatural deaths – which include suicides and assisted suicides. These deaths are then examined by the police and medical officers. The Federal Statistics Office does not routinely collect data on assisted suicide, as recorded causes of death do not distinguish between suicide and assisted suicide. Evidence from a review of 748 cases of suicide assisted by a right-to-die organisation between 1990 and 2000 indicate that cases were referred to the authorities as required; for example, all assisted suicides in the City of Zurich between 1990 and 2000 were duly reported to the authorities.<sup>688</sup>

## Part Six – Comparative table of international legislation

	Assisted suicide	Euthanasia	Eligibility criteria	The request	Medical involvement	Regulation
<p><b>The Netherlands</b></p> <p><i>Termination of Life on Request and Assisted Suicide Act 2001</i></p>	Yes	Yes	<p>Patient must be:</p> <ul style="list-style-type: none"> <li>– at least 12 years old;</li> <li>– competent;</li> <li>– experiencing constant and unbearable physical or psychological suffering with no prospect of improvement.</li> </ul> <p>The consent of parents must be obtained in cases involving 12-16 year olds.</p> <p>Separate regulations known as the Groningen Protocol outline the criteria to be taken into account when ending the life of severely disabled neonates.</p>	<p>The request must:</p> <ul style="list-style-type: none"> <li>– be voluntary;</li> <li>– be carefully considered;</li> <li>– have persisted over time.</li> </ul> <p>Dutch law recognises the validity of advance directives requesting assisted suicide or euthanasia.</p>	<p>The physician must:</p> <ul style="list-style-type: none"> <li>– be satisfied that the patient’s request is voluntary and well considered;</li> <li>– be satisfied that the patient’s suffering is unbearable and there is no prospect of improvement;</li> <li>– inform the patient of their situation and their prospects;</li> <li>– come to the conclusion, together with the patient, that there is no other alternative;</li> <li>– consult with at least one other independent physician who confirms the prognosis and that the due care criteria have been satisfied;</li> <li>– carry out the death in a medically appropriate fashion and be present at the time of death.</li> </ul> <p>Doctors can refuse to perform procedures to terminate life.</p>	<p>Doctors must report the death to the municipal coroner. The coroner will inform one of five regional review committees, who will assess whether the law has been complied with. These committees include a physician and an ethics expert, and are chaired by a lawyer. If the conditions have not been met, it is reported to the public prosecutor for further investigation and action. The committees issue a joint annual report to the ministry of justice.</p>

	Assisted suicide	Euthanasia	Eligibility criteria	The request	Medical involvement	Regulation
<b>Belgium</b>  <i>Belgian Act on Euthanasia 2002</i>	Not regulated (not a criminal offence, but not explicitly permitted in law either)	Yes	Patient must be: <ul style="list-style-type: none"> <li>– a competent adult or emancipated minor;</li> <li>– suffering from constant and unbearable physical or psychological suffering which cannot be cured;</li> <li>– a Belgian resident;</li> <li>– conscious at the time of making the request.</li> </ul> The Belgian Parliament voted to extend euthanasia for competent children of all ages in February 2014 where the child has a terminal and incurable illness; experiences “constant and unbearable suffering”; and death is expected to occur within a “brief period”. Parental consent is required.	The request must be: <ul style="list-style-type: none"> <li>– made in writing;</li> <li>– made on a voluntary basis;</li> <li>– made repeatedly.</li> </ul> Belgian law recognises the validity of advance directives requesting euthanasia.	The physician must: <ul style="list-style-type: none"> <li>– confirm that the patient meets the eligibility criteria;</li> <li>– inform the patient of their diagnosis and prognosis;</li> <li>– discuss with the patient their prognosis and all other therapeutic and palliative care options available to them;</li> <li>– have a second independent medical practitioner confirm the diagnosis and prognosis;</li> <li>– discuss the patient’s request with the medical team and family members if requested.</li> </ul> The Act includes a conscience clause. An objecting physician must explain this to the patient, and, if requested to do so, hand over the medical records to another designated physician.	Medical practitioner must submit a form to the Federal Control and Evaluation Commission, made up of 16 members who are medical practitioners, legal experts and philosophers. The Commission carries out an <i>ex posteriori</i> control with regard to compliance with the law. Should the Commission feel the law has not been complied with, the case is referred to the public prosecutor.

	Assisted suicide	Euthanasia	Eligibility criteria	The request	Medical involvement	Regulation
<p><b>Luxembourg</b></p> <p><i>Law on the Right to Die with Dignity 2009</i></p>	Yes	Yes	<p>Patient must be:</p> <ul style="list-style-type: none"> <li>– a competent adult;</li> <li>– conscious at the time of the request;</li> <li>– in a severe and incurable terminal medical situation, with constant and unbearable physical or mental suffering, with no prospect of improvement.</li> </ul>	<p>The request must be:</p> <ul style="list-style-type: none"> <li>– made voluntarily, after reflection, and if necessary, repeated;</li> <li>– made in writing</li> </ul> <p>The law in Luxembourg recognises the validity of advance directives requesting assistance in dying.</p>	<p>The physician must:</p> <ul style="list-style-type: none"> <li>– inform the patient of the prognosis and all therapeutic interventions or palliative care available;</li> <li>– be satisfied that the request has been made voluntarily;</li> <li>– have several interviews with the patient to ascertain persistence of physical or mental suffering and their wish to die;</li> <li>– consult another doctor as to the severe and incurable nature of the disorder;</li> <li>– if necessary, discuss the request with the person of trust appointed in end of life provisions or at the time of their request for euthanasia or physician-assisted suicide.</li> </ul> <p>The law contains a conscientious objection clause. Objecting physicians must notify the patient and pass the medical notes to an alternative doctor.</p>	<p>Within 9 days of helping a patient end his or her life, a doctor must notify the Commission of Control and Assessment, made up of 9 members – including 3 medical doctors – who will verify compliance with the law. If it believes the requirements of the law have not been met, they will refer the case to either the public prosecutor (for criminal sanctions) or the medical council (for professional sanctions).</p>

	Assisted suicide	Euthanasia	Eligibility criteria	The request	Medical involvement	Regulation
<b>Switzerland</b>  <i>Art. 115 Swiss Criminal Code 1942</i>	Yes	No	<p>Assisted suicide permitted as long as the motive for doing so is not selfish, e.g., not for personal gain.</p> <p>Development of Swiss law has made clear that the person requesting assistance must have capacity.</p>	There is no legislative process for requesting assisted dying.	<p>The law does not require a physician to be involved – although as under Swiss law they are the only persons who can prescribe lethal substances, they in effect act as gatekeepers to assisted suicide.</p> <p>The Swiss Academy of Medical Sciences (SAMS) guidance states that participating in assisted suicide is a matter of individual conscience, and that physicians may assist in the suicide of a patient who is approaching the end of life, providing that the person has capacity and has made a voluntary, persistent, and well-considered request.</p>	<p>There is no central regulatory body. Cantonal health regulations require healthcare workers to notify the police of all unnatural deaths – which include suicide and assisted suicide. These deaths are then examined by the police and medical officers.</p> <p>The Federal Statistics Office does not routinely collect data on assisted suicide – recorded causes of death do not differentiate between suicide and assisted suicide.</p>

	Assisted suicide	Euthanasia	Eligibility criteria	The request	Medical involvement	Regulation
<b>Oregon</b>  <i>Death with Dignity Act 1994</i>	Yes	No	<p>The patient must:</p> <ul style="list-style-type: none"> <li>– be at least 18 years old;</li> <li>– be a resident of Oregon;</li> <li>– be deemed capable of making their own decisions;</li> <li>– have a terminal illness that will cause their death within six months.</li> </ul>	<p>The request must:</p> <ul style="list-style-type: none"> <li>– be made orally by the patient in the first instance;</li> <li>– be made in writing at least 15 days after the initial oral request;</li> <li>– be signed by two independent witnesses (at least one of whom is not a relative or employed by the healthcare facility) who confirm that the patient is competent, acting voluntarily, and not being coerced</li> </ul>	<p>The physician must:</p> <ul style="list-style-type: none"> <li>– refer the patient to another physician for medical confirmation of the diagnosis, and for a determination that the patient is capable and acting voluntarily;</li> <li>– notify the patients of alternatives such as palliative care and pain management;</li> <li>– refer the patient to counselling if they believe them to be suffering from a psychiatric or psychological disorder causing impaired judgement;</li> <li>– encourage the patient to notify their next of kin;</li> <li>– inform the patient that they can rescind the request at any time;</li> <li>– directly dispense the necessary medication or with the patient's written consent, delegate these duties to a pharmacist.</li> </ul> <p>Doctors cannot be compelled to participate. If they are unwilling to carry out a patient's request, they are required to transfer medical records to an alternative health care provider.</p>	<p>Doctors must inform the Oregon Department of Health of any lethal prescription they write. The Department is required by the Act to develop a system for monitoring and collecting information on assisted suicide. It would be the responsibility of the Department to inform the Public Prosecutor in suspected cases of abuse.</p> <p>The Department generates annual statistical reports based on the information collected.</p>

	Assisted suicide	Euthanasia	Eligibility criteria	The request	Medical involvement	Regulation
<b>Washington</b>  <i>Death with Dignity Act 2008</i>	Yes	No	The patient must: <ul style="list-style-type: none"> <li>– be a competent adult;</li> <li>– be a resident of Washington;</li> <li>– be suffering from a terminal illness expected to cause their death within six months.</li> </ul>	The request must: <ul style="list-style-type: none"> <li>– be made orally by the patient in the first instance;</li> <li>– be made in writing at least 15 days after the initial oral request;</li> <li>– be made in the presence of at least two witnesses, who confirm that the patient is competent, acting voluntarily, and is not being coerced.</li> </ul>	The physician must: <ul style="list-style-type: none"> <li>– confirm that the patient meets the eligibility criteria of the Act;</li> <li>– inform the patient of their diagnosis, prognosis and all options for their treatment and care;</li> <li>– refer the patient to a second physician for medical confirmation of the diagnosis and prognosis, and for a determination that the patient is competent and acting voluntarily;</li> <li>– refer the patient to counselling if they believe them to be suffering from a psychiatric or psychological disorder causing impaired judgement;</li> <li>– inform the patient that they can rescind the request at any time</li> <li>– directly dispense the necessary medication or with the patient's written consent, delegate these duties to a pharmacist.</li> </ul>	Doctors must inform the Washington Department of Health of any lethal prescription they write within 30 days. The Department is required by the Act to adopt rules to facilitate the collection of information, and to generate annual statistical reports.



	Assisted Suicide	Euthanasia	Eligibility criteria	The request	Medical involvement	Regulation
<b>Vermont</b>  <i>Patient Choice and Control at the End of Life Act 2013</i>	Yes	No	The patient must: <ul style="list-style-type: none"> <li>– be aged 18 or over;</li> <li>– have a terminal illness expected to cause their death within six months;</li> <li>– be capable;</li> <li>– be a Vermont resident;</li> <li>– be making an informed decision.</li> </ul>	The request must: <ul style="list-style-type: none"> <li>– be made orally by the patient in the first instance;</li> <li>– be made in writing at least 15 days after the initial oral request;</li> <li>– be signed by two independent witnesses (at least one of whom is not a relative or employed by the healthcare facility) who confirm that the patient is competent, acting voluntarily, and not being coerced</li> </ul>	The physician must: <ul style="list-style-type: none"> <li>– determine that the patient meets the eligibility criteria;</li> <li>– inform the patient, verbally and in writing, of their diagnosis, prognosis, and all treatment options;</li> <li>– refer the patient to a second physician for medical confirmation of the diagnosis and prognosis, and a determination that the patient is capable, acting voluntarily, and making an informed decision;</li> <li>– either verify that the patient does not have impaired judgement, or refer the patient for evaluation by a specialist;</li> <li>– inform the patient that they can rescind the request at any time;</li> <li>– directly dispense the necessary medication or with the patient's written consent, delegate these duties to a pharmacist.</li> </ul>	Doctors must file a report with the Vermont Department of Health detailing compliance with the law after every case of assisted suicide.

## Glossary

**Double effect:** The doctrine of double effect means that a physician may use pain relief which may, in some circumstances, risk hastening death if the intention is to relieve the patient's pain and suffering and the dosage is proportionate to that intention.

**End-of-life care:** refers to the total care of a person with an advanced incurable illness and does not just equate with dying. The end-of-life care phase may last for days, weeks, months or even longer. It is defined as care that helps those with advanced progressive, incurable illness to live as well as possible until they die. It includes the prevention and relief of suffering through the assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

**Euthanasia:** a deliberate act – usually the administration of lethal drugs by a physician or another person – with the intention of ending a patient's life.

**Palliative care:** an approach that can improve the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

**Physician-assisted dying:** an overarching term to describe physician involvement in measures intentionally designed to terminate a patient's life. This may include knowingly and intentionally providing a person with the knowledge and/or means required to end his or her life, including counselling about lethal doses of drugs and prescribing such lethal doses or supplying the drugs. Administration of the drug may be by the individual him or herself (physician-assisted suicide) or by the physician or another person (euthanasia).

**Suicide:** an act by an individual to intentionally end his or her life. Related terms include:

- *Assisted suicide* – where this involves assistance or encouragement from another person; and
- *Physician-assisted suicide* – where the assistance or encouragement is provided by a physician.

**Terminal illness:** an illness that cannot be cured and is likely to cause death within weeks or months.

**Withholding or withdrawing life-prolonging treatment:** a decision to withdraw or withhold life-prolonging treatment is made when it is no longer able to benefit a patient who lacks capacity, where a patient with capacity refuses it or where there is a valid advance refusal. Ongoing care and support for the patient continues to be provided.

## Endnotes

- 1 Parliamentary and Health Service Ombudsman (2015) *Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end-of-life care*. PHSO: London.
- 2 Neuberger J (2013) *More care, less pathway – a review of the Liverpool Care Pathway*. Independent Review of the Liverpool Care Pathway: London.
- 3 Dixon J, King D, Matosevic T et al. (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics/Marie Curie: London.
- 4 Economist Intelligence Unit (2010) *The quality of death. Ranking end-of-life care across the world. A report from the Economist Intelligence Unit commissioned by LIEN Foundation*. Economist Intelligence Unit: London.
- 5 Economist Intelligence Unit (2015) *The 2015 quality of death index. Ranking palliative care across the world. A report from the Economist Intelligence Unit commissioned by LIEN Foundation*. Economist Intelligence Unit: London.
- 6 Dixon J, King D, Matosevic T et al. (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics/Marie Curie: London.
- 7 House of Commons Health Committee (2004) *Palliative Care: Fourth Report of Session 2003-04. Volume I*. House of Commons: London.
- 8 Royal College of Physicians (2007) *Palliative care services: meeting the needs of patients. Report of a working party*. RCP: London.
- 9 Parliamentary and Health Service Ombudsman (2015) *Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end-of-life care*. PHSO: London.
- 10 Dying Matters (2015) *Concerns about end-of-life care*. Available at: <http://www.dyingmatters.org/page/concerns-about-end-life-care> (Accessed 10 November 2015).
- 11 Office for National Statistics (2015) *National population projections, 2014-based statistical bulletin*. ONS: London.
- 12 Select Committee on Public Service and Demographic Change (2013) *Ready for Ageing?* (1st Report, Session 2012-13, HL Paper 140) Available at: <http://www.publications.parliament.uk/pa/ld201213/ldselect/ldpublic/140/140.pdf> (Accessed 4 December 2015). p.58.
- 13 "Liverpool Care Pathway: Your experiences". *BBC News Online*, 13 July 2013. Available at: <http://www.bbc.co.uk/news/health-23301360> (Accessed 21 September 2015).
- 14 Hall M "Elderly wife 'left to die' after hospital put her on end-of-life programme". *The Telegraph*, 8 April 2013. Available at: <http://www.telegraph.co.uk/news/health/9979868/Elderly-wife-left-to-die-after-hospital-put-her-on-end-of-life-programme.html> (Accessed 21 September 2015).
- 15 BBC News Online. "Liverpool Care Pathway: 'They told my family I was dying.'" *BBC News Online*, 15 August 2013. Available at: <http://www.bbc.co.uk/news/health-23698071> (Accessed 21 September 2015).
- 16 Donnelly L "Leading doctor's fears about Liverpool Care Pathway". *The Telegraph*, 3 March 2013. Available at: <http://www.telegraph.co.uk/news/health/news/9904650/Leading-doctors-fears-about-Liverpool-Care-Pathway.html> (Accessed 21 September 2015).
- 17 Pemberton M "The Liverpool Care Pathway to dignity in death". *The Telegraph*, 13 January 2014. Available at: <http://www.telegraph.co.uk/news/health/elder/9796968/The-Liverpool-Care-Pathway-to-dignity-in-death.html> (Accessed 21 September 2015).
- 18 Neuberger J (2013) *More Care, Less Pathway: A Review of the Liverpool Care Pathway*. Independent Review of the Liverpool Care Pathway: London.
- 19 Leadership Alliance for the Care of Dying People (2014) *One chance to get it right: improving people's experience of care in the last few days and hours of life*. LACDP: London.
- 20 Dixon J, King D, Matosevic T et al. (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics/Marie Curie: London. p. 22

- 21 Dixon J, King D, Matosevic T *et al.* (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics/Marie Curie: London. p. 22.
- 22 Office for National Statistics (2014) *Deaths registered in England and Wales: statistical bulletin*. ONS: London.
- 23 Department of Health, NHS (2008) *End-of-life Care Strategy: Promoting high quality care for all adults at the end-of-life*. DH: London.
- 24 House of Lords, *Hansard*, 23 October 2015, col. 910.
- 25 Department of Health (2015) *One Chance to Get it Right: One Year On Report. An overview of progress on commitments made in One Chance to Get it Right: the system-wide response to the Independent Review of the Liverpool Care Pathway*. DH: London.
- 26 National Institute for Health and Care Excellence (2013) *Quality standards for end of life care for adults: NICE quality standard 13*. NICE: London.
- 27 NHS England, Care Quality Commission, Health Education England *et al.* (2014) *Five Year Forward View*. NHS England: London.
- 28 Parliamentary and Health Service Ombudsman (2015) *Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end-of-life care*. PHSO: London.
- 29 House of Commons Public Administration and Constitutional Affairs Committee (2015) *Follow-up to PHSO Report: Dying without Dignity. First Report of Session 2015-16*. House of Commons: London.
- 30 National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. National Palliative and End of Life Care Partnership: London.
- 31 Public Health England (2015) "Plans for a new specialist palliative care data collection in England: what this means for provider services, commissioners, clinicians, patients and the public." PHE: London.
- 32 Care Quality Commission. Press release: Most hospices are 'good' or better, says CQC, 10 October 2015. CQC. Available at: <http://www.cqc.org.uk/content/most-hospices-are-%E2%80%98good%E2%80%99-or-better-says-cqc> (accessed 15 October 2015).
- 33 The full text of the Bill can be found online at: <http://www.publications.parliament.uk/pa/bills/lbill/2015-2016/0013/16013.pdf> (accessed 28 September 2015).
- 34 Access to Palliative Care Bill [HL] clause 2 (2) <http://www.publications.parliament.uk/pa/bills/lbill/2015-2016/0013/16013.pdf> (accessed 28 September 2015).
- 35 Access to Palliative Care Bill, clause 3, <http://www.publications.parliament.uk/pa/bills/lbill/2015-2016/0013/16013.pdf> (accessed 28 September 2015).
- 36 Office for National Statistics (2015) *National population projections, 2014-based statistical bulletin*. ONS: London.
- 37 Dixon J, King D, Matosevic T *et al.* (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics/Marie Curie: London. p. 22.
- 38 Marie Curie, Bevan Foundation (2014) *Death and dying in Wales: an analysis of inconsistencies in access to specialist palliative care and hospital activity in the last year of life*. Marie Curie/Bevan Foundation: Cardiff. p.3.
- 39 Office for National Statistics (2014) *Mortality statistics: deaths registered in 2013*. ONS: London.
- 40 Welsh Government (2013) *Together for Health – Delivering End-of-life Care: A Delivery Plan up to 2016 for NHS Wales and its Partners*. Welsh Government: Cardiff.
- 41 Welsh Assembly Government (2007) *One Wales – A Progressive Agenda for the Government of Wales*. Welsh Assembly Government: Cardiff.
- 42 Palliative Care Implementation Board (2011) *Dying Well Matters – One Wales: 3 Years On (2008-2011)*. PCIB: Cardiff.
- 43 Further information on the Cancer Network Information System can be found at: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=361&pid=38200> (Accessed 21 September 2015).

- 44 Further information about iWantGreatCare can be found at:  
<https://www.iwantgreatcare.org/> (Accessed 6 November 2015).
- 45 NHS Wales (2009) *Dying Well Matters – Listening to Patients and Families to improve care*. NHS Wales: Cardiff.
- 46 Francis, H “Byw Nawr: Live now... but plan for the inevitable”. *Dying Matters Blog*, 2 September 2014. Available at: <http://www.dyingmatters.org/blog/byw-nawr-live-now-plan-inevitable> (Accessed 21 September 2015).
- 47 NHS Wales, Welsh Government (2014) *Together for Health – End-of-life Care Delivery Plan: Annual Report 2014*. NHS Wales/Welsh Government: Cardiff.
- 48 Office for National Statistics (2015) *National population projections, 2014-based statistical bulletin*. ONS: London.
- 49 Dixon J, King D, Matosevic T *et al.* (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics/Marie Curie: London. p.22.
- 50 National Records of Scotland (2014) *Scotland’s Population 2013 – the Registrar General’s Annual Review of Demographic Trends*. NRS: Edinburgh.
- 51 Scottish Government (2008) *Living and Dying Well: a national action plan for palliative and end-of-life care in Scotland*. Scottish Government: Edinburgh.
- 52 Scottish Government (2012) *Living and Dying Well – Reflecting on Progress. A national overview report on palliative and end of life care*. Scottish Government: Edinburgh.
- 53 NHS Scotland, Healthcare Improvement Scotland (2013) *Scottish Palliative Care Guidelines*. NHS Scotland/HIS: Edinburgh.
- 54 More information on the NHS Inform Portal can be found at:  
<http://www.nhsinform.co.uk/palliativecare/> (Accessed 4 December 2015).
- 55 Scottish Government, NHS Scotland (2014) *Caring for people in the last days and hours of life*. Scottish Government/NHS Scotland: Edinburgh.
- 56 Scottish Government (2014) *Strategic Framework for Action*. Available at:  
<http://www.palliativecarescotland.org.uk/content/publications/Framework-for-Action---Development-Paper.pdf> (Accessed 4 December 2015).
- 57 Health and Sport Committee (2015) *We need to talk about Palliative Care*. Scottish Parliament: Edinburgh.
- 58 Office for National Statistics (2015) *National population projections, 2014-based statistical bulletin*. ONS: London.
- 59 Dixon J, King D, Matosevic T *et al.* (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics/Marie Curie: London. p.22.
- 60 Northern Ireland Statistics and Research Agency (2015) *Registrar General Annual Northern Ireland Report 2014*. Department of Finance and Personnel: Belfast.
- 61 Northern Ireland Statistics and Research Agency (2015) *Registrar General Annual Northern Ireland Report 2014*. Department of Finance and Personnel: Belfast.
- 62 Department for Health, Social Services and Public Safety Northern Ireland (2010) *Living Matters, Dying Matters: A palliative and end-of-life strategy for adults in Northern Ireland*. DHSSPSNI: Belfast.
- 63 Department for Health, Social Services and Public Safety Northern Ireland (2010) *Living Matters, Dying Matters: A palliative and end-of-life strategy for adults in Northern Ireland*. DHSSPSNI: Belfast. p.3.
- 64 Department for Health, Social Services and Public Safety Northern Ireland (2010) *Living Matters, Dying Matters: A palliative and end-of-life strategy for adults in Northern Ireland*. DHSSPSNI: Belfast. p.65.
- 65 Department for Health, Social Services and Public Safety Northern Ireland (2010) *Living Matters, Dying Matters: A palliative and end-of-life strategy for adults in Northern Ireland*. DHSSPSNI: Belfast. p.25.
- 66 Northern Ireland Assembly Written Question AQW 38892/11-15, 2014.  
<http://aims.niassembly.gov.uk/questions/printquestionssummary.aspx?docid=214360> (Accessed 23 September 2015).
- 67 Department of Health, Social Services and Public Safety Northern Ireland (2011) *Transforming your care: A Review of Health and Social Care in Northern Ireland*. DHSSPSNI: Belfast.

- 68 Health and Social Care Board, Marie Curie (2014) *Transforming Your Palliative and End-of-life Care Update: moving forward with eight initiatives*. HSC/Marie Curie: Belfast.
- 69 Northern Ireland Assembly Written Question, AQW 40629/11-15, 2014. Available at: [http://aims.niassembly.gov.uk/questions/writtensearchresults.aspx?qf=0&qfv=1&ref=AQW\\_40629/11-15](http://aims.niassembly.gov.uk/questions/writtensearchresults.aspx?qf=0&qfv=1&ref=AQW_40629/11-15) (Accessed 23 September 2015).
- 70 Public Health Agency, Health and Social Care Board (2015) *Commissioning Plan 2014/15*. PHA/HSC: Belfast. p.154.
- 71 More information available at: <http://www.dhsspsni.gov.uk/sqsd-standards-service-frameworks> (Accessed 23 September 2015).
- 72 Department of Health, Social Services and Public Safety Northern Ireland (2013) *Cancer Prevention, Treatment and Cure Service Framework*. DHSSPSNI: Belfast. pp.38-40.
- 73 Department of Health, Social Services and Public Safety Northern Ireland (2015) *Learning Disability Service Framework*. DHSSPSNI: Belfast. p.21.
- 74 Department of Health, Social Services and Public Safety Northern Ireland (2015) *Service framework for older people*. DHSSPSNI: Belfast. p.34.
- 75 Hughes-Hallett T, Craft A, Davies C (2011) *Funding the Right Care and Support for Everyone: Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review*. Palliative Care Funding Review: London.
- 76 NHS England (2015) *Developing a new approach to palliative care funding*. NHS England: London.
- 77 Welsh Government. £6.4 million of funding for specialist end-of-life care. *Welsh Government Press Release*, 18 August 2014. Available at: <http://gov.wales/newsroom/healthandsocialcare/2014/140815fundingforendoflifecare/?lang=en> (Accessed 21 September 2015)
- 78 Payne J (2010) *SPICe Briefing: Palliative Care (Scotland) Bill*. Scottish Parliament Information Centre: Edinburgh.
- 79 Economist Intelligence Unit (2015) *The 2015 quality of death index: ranking palliative care across the world. A report from the Economist Intelligence Unit commissioned by LIEN Foundation*. Economist Intelligence Unit: London.
- 80 Royal College of Physicians (2007) *Palliative care services: meeting the needs of patients. Report of a working party*. RCP: London. p.3.
- 81 Help the Hospices (2014) *Hospice Accounts – Analysis of the accounts of UK independent voluntary hospices for the year ended March 2013*. HtH: London. pp.13-16.
- 82 Help the Hospices (2014) *Hospice Accounts – Analysis of the accounts of UK independent voluntary hospices for the year ended March 2013*. HtH: London. p.14.
- 83 National Audit Office (2008) *End-of-life care – Results of censuses of Independent Hospices & NHS Palliative Care Providers*. NAO: London.
- 84 Hughes-Hallett T, Craft A, Davies C (2011) *Funding the Right Care and Support for Everyone: Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review*. Palliative Care Funding Review: London.
- 85 Scottish Executive Health Department. *NHS HDL (2003) 18 – Funding of Specialist Palliative Care Provided by Independent Voluntary Hospices in Scotland*. Available at: [http://www.sehd.scot.nhs.uk/mels/HDL2003\\_18.pdf](http://www.sehd.scot.nhs.uk/mels/HDL2003_18.pdf) (Accessed 4 December 2015).
- 86 Scottish Government. *CEL 12 (2012) – A Partnership for Better Palliative and End of Life Care: Creating a New Relationship Between Independent Adult Hospices and NHS Boards in Scotland*. Available at: [http://www.sehd.scot.nhs.uk/mels/CEL2012\\_12.pdf](http://www.sehd.scot.nhs.uk/mels/CEL2012_12.pdf) (Accessed 8 December 2015).
- 87 Audit Scotland (2008) *Review of palliative care services in Scotland*. Audit Scotland: Edinburgh.
- 88 Scottish Government (2010) *Free Personal & Nursing Care: Public Information Leaflet*. Available at: <http://www.gov.scot/Resource/Doc/305166/0095748.pdf> (Accessed 14 October 2015).
- 89 Department of Health, Social Services and Public Safety (2013) *Who Cares? The Future of Adult Care and Support in Northern Ireland*. DHSSPSNI: Belfast. p.9.

- 90 House of Commons Health Committee (2015) *End-of-life Care: Fifth Report of Session 2014-15*. The Stationery Office: London.
- 91 Department of Health (2015) Government Response to the House of Commons Health Select Committee Report on End of Life Care (Fifth Report of Session 2014-15). DH: London.
- 92 Marie Curie, Bevan Foundation (2014) *Death and dying in Wales: an analysis of inconsistencies in access to specialist palliative care and hospital activity in the last year of life*. Marie Curie/Bevan Foundation: Cardiff.
- 93 Clark D, Armstrong M, Allan A *et al*. "Imminence of death among hospital inpatients: Prevalent cohort study". *Palliat Med* 2014; **28**(6): 474-79.
- 94 Royal College of Physicians, Marie Curie (2014) *National care of the dying audit for hospitals, England*. RCP: London.
- 95 Reid C, Gibbins J, Bloor S, *et al*. "Healthcare professionals' perspectives on delivering end-of-life-care within acute hospital trusts: a qualitative study". *BMJ Support Palliat Care* 2015; **5**(5): 490-5.
- 96 Reid C, Gibbins J, Bloor S, *et al*. "Healthcare professionals' perspectives on delivering end-of-life-care within acute hospital trusts: a qualitative study". *BMJ Support Palliat Care* 2015; **5**(5): 490-5.
- 97 Gott M, Ingleton C, Bennett I *et al*. "Transitions to palliative care in acute hospitals in England: qualitative study". *BMJ* 2011; **342**: d1773.
- 98 Gardiner C, Cobb M, Gott M *et al*. "Barriers to providing palliative care for older people in acute hospitals". *Age and Ageing* 2011; **40**: 233-238.
- 99 Wright B, Forbes K "Haematologists' perceptions of palliative care and specialist palliative care referral: a qualitative study". *BMJ Support Palliat Care* 2014; **0**: 1-7.
- 100 Gardiner C, Cobb M, Gott M *et al*. "Barriers to providing palliative care for older people in acute hospitals". *Age and Ageing* 2011; **40**: 233-238.
- 101 Gardiner C, Brereton L, Gott M *et al*. "Exploring health professionals' views regarding the optimum physical environment for palliative and end-of-life care in the acute hospital setting: a qualitative study". *BMJ Support Palliat Care* 2011; **1**: 162-166.
- 102 NHS Wales, Welsh Government (2014) *Together for Health: End of Life Care Delivery Plan: Annual Report 2014*. NHS Wales/Welsh Government: Cardiff. p.11.
- 103 BBC News Online. "GP shortages put pressure on doctors and patients". *BBC News Online*, 2 March 2015. Available at: <http://www.bbc.co.uk/news/health-31550423> (Accessed 14 October 2015).
- 104 Mason B, Epiphaniou E, Nanon V *et al*. "Coordination of care for individuals with advanced progressive conditions: a multi-site ethnographic and serial interview study". *Br J Gen Pract* 2013 Aug; **63**(613): e580-e588.
- 105 Oishi A, Murtagh FEM "The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals." *Palliat Med* 2014; **28**(9): 1081-1098.
- 106 Oishi A, Murtagh FEM "The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals." *Palliat Med* 2014; **28**(9): 1081-1098. p.1093.
- 107 Mitchell H, Noble S, Finlay I *et al*. "Defining the palliative care patient: its challenges and implications for service delivery". *BMJ Support Palliat Care* 2012; **3**: 46-52.
- 108 Taubert M, Noble S, Nelson A "What challenges good palliative care provision out-of-hours? A qualitative interview study of out-of-hours general practitioners". *BMJ Support Palliat Care* 2011; **1**: 13-18.
- 109 Magee C, Koffman J. "Supporting general practitioners to provide out-of-hours palliative care". *BMJ Support Palliat Care* 2014; **4**(1): 107.
- 110 Taubert M, Nelson A "Out-of-hours GPs and palliative care – a qualitative study exploring information exchange and communication issues". *BMC Palliative Care* 2010; **9**: 18.

- 111 Taubert M, Noble S, Nelson A "What challenges good palliative care provision out-of-hours? A qualitative interview study of out-of-hours general practitioners". *BMJ Support Palliat Care* 2011; **1**: 13-18.
- 112 Murtaugh FEM, Bausewein C, Verne J *et al.* "How many people need palliative care? A study developing and comparing methods for population-based estimates". *Palliat Med* 2014; **28**(1): 49-58.
- 113 Higginson IJ "Health care needs assessment: palliative and terminal care." In Stevens A and Rafferty J (eds.) (1997) *Health care needs assessment*. Radcliffe Medical Press: Oxford. pp.1-28.
- 114 Rosenwax LK, McNamara B, Blackmore AM *et al.* "Estimating the size of a potential palliative care population." *Palliat Med* 2005; **19**(7): 556-62.
- 115 Gomez-Batiste X, Martinez-Munoz M, Blay C *et al.* "Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach." *Curr Opin Support Palliat Care* 2012; **6**(3): 371-378.
- 116 Harrison N, Cavers D, Campbell C *et al.* "Are UK primary care teams formally identifying patients for palliative care before they die?" *Br J Gen Pract* 2012; **62**(598):e344-e352.
- 117 Healthcare Improvement Scotland (2013) *Palliative and end-of-life indicators*. NHS Scotland: Edinburgh.
- 118 Marie Curie, Bevan Foundation (2014) *Death and dying in Wales: an analysis of inconsistencies in access to specialist palliative care and hospital activity in the last year of life*. Marie Curie/Bevan Foundation: Cardiff.
- 119 Information drawn from the oral evidence presented to the Health Select Committee on 20 January 2015. Available at: <http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/health-committee/end-of-life-care/oral/17687.html> (Accessed 9 November 2015).
- 120 House of Commons Health Committee (2014) *Oral evidence: end-of-life care*. HC 805, Tuesday 20 January 2014. Available at: <http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/health-committee/end-of-life-care/oral/17687.html> (Accessed 22 September 2015).
- 121 Mason B, Epiphaniou E, Nanon V *et al.* "Coordination of care for individuals with advanced progressive conditions: a multi-site ethnographic and serial interview study". *Br J Gen Pract* 2013 Aug; **63**(612): e580-e588.
- 122 Temel JS, Greer JA, Muzinkansky A *et al.* "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer". *New Eng J Med* 2010; **363**: 733-42.
- 123 Choice in End of Life Programme Board (2015) *What's important to me: A Review of Choice in End-of-life Care*. Choice in End of Life Programme Board: London.
- 124 Marie Curie (2015) *Changing the conversation: Care and support for people with a terminal illness now and in the future*. Marie Curie: London.
- 125 International Association for the Study of Pain (2012) *International Association for the Study of Pain Taxonomy*. Available at: <http://www.iasp-pain.org/Taxonomy> (Accessed 13 November 2015).
- 126 Bender JL, Hohenadel J, Wong J *et al.* "What Patients with Cancer Want to Know About Pain: A Qualitative Study". *J Pain Symp Manage* 2008; **35**: 177-87.
- 127 British Pain Society (2010) *Managing cancer pain – information for patients: From the British Pain Society, supported by the Association of Palliative Medicine and the Royal College of General Practitioners*. Available at: [https://www.britishpainsociety.org/static/uploads/resources/files/book\\_cancer\\_pain\\_patients\\_1.pdf](https://www.britishpainsociety.org/static/uploads/resources/files/book_cancer_pain_patients_1.pdf) (Accessed 13 November 2015).
- 128 Solano JP, Gomes B, Higginson IJ "A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease". *J Pain Symptom Manage* 2006; **31**(1): 58-69.
- 129 See, for example, the NICE guidelines *Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults (CG140)* (2012), available at: <https://www.nice.org.uk/guidance/cg140> (Accessed 13 November 2015); NHS Scotland *Scottish Palliative Care Guidelines* (2014), available at: <http://www.palliativecareguidelines.scot.nhs.uk/guidelines/pain/pain-management.aspx> (Accessed 13 November 2015).



- 130 "Principles underpinning effective pain management" in Sharma M, Simpson KH, Bennett MI *et al.* (eds) (2014) *Oxford Specialist Handbooks In Oncology: Complex Management of Complex Cancer Pain*. Oxford University Press: Oxford.
- 131 Hicks F, Rees E "A 'pain-free' death". *British Medical Bulletin* 2008; **88**: 23-41.
- 132 Office for National Statistics (2015) *National Survey of Bereaved People (VOICES), 2014*. ONS: London.
- 133 Weiss SC, Emanuel LL, Fairclough DL *et al.* "Understanding the experience of pain in terminally ill patients". *Lancet* 2001; **357**: 1311-15.
- 134 Shucksmith J, Carlebach S, Whittaker V (2013) *Dying – Discussing and planning for the end of life - British Social Attitudes 30*. NatCen Social Research. Available at: [http://www.bsa.natcen.ac.uk/media/38850/bsa\\_30\\_dying.pdf](http://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf) (Accessed 9 November 2015).
- 135 Cox K, Bird L, Arthur A *et al.* "Public attitudes to death and dying in the UK: a review of published literature". *BMJ Support Palliat Care* 2013; **3**: 37–45.
- 136 Seymour J, Kennedy S, Arthur A *et al.* (2009) *Public attitudes to death, dying and bereavement: a systematic synthesis – Executive summary*. <http://www.nottingham.ac.uk/research/groups/srcc/documents/projects/srcc-project-summary-public-attitudes.pdf> (accessed 8 March 2015).
- 137 Sue Ryder, Demos (2013) *A time and a place: what people want at the end of life*. Available at: <http://www.sueryder.org/~media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx> (Accessed 9 March 2015).
- 138 Sue Ryder, Demos (2013) *A time and a place: what people want at the end of life*. Available at: <http://www.sueryder.org/~media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx> (Accessed 9 March 2015).
- 139 ComRes (2015) *National Council for Palliative Care – Public Opinion on Death and Dying – 29-30 April 2015*. [http://comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care\\_Public-opinion-on-death-and-dying.pdf](http://comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care_Public-opinion-on-death-and-dying.pdf) (accessed 25 August 2015).
- 140 Bowling A, Iliffe S, Kessel A *et al.* "Fear of dying in an ethnically diverse society: cross-sectional studies of people aged 65+ in Britain". *Postgrad Med J* 2010; **86**: 197-202.
- 141 Pollock K "Is home always the best and preferred place of death?" *BMJ* 2015; **351**: h4855. doi: 10.1136/bmj.h4855.
- 142 Shucksmith J, Carlebach S, Whittaker V (2013) *Dying – Discussing and planning for the end of life - British Social Attitudes 30*. NatCen Social Research. Available at: [http://www.bsa.natcen.ac.uk/media/38850/bsa\\_30\\_dying.pdf](http://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf) (Accessed 9 November 2015).
- 143 Cox K, Bird L, Arthur A *et al.* "Public attitudes to death and dying in the UK: a review of published literature". *BMJ Support Palliat Care* 2013; **3**: 37–45.
- 144 Seymour J, Kennedy S, Arthur A *et al.* (2009) *Public attitudes to death, dying and bereavement: a systematic synthesis – Executive summary*. <http://www.nottingham.ac.uk/research/groups/srcc/documents/projects/srcc-project-summary-public-attitudes.pdf> (accessed 8 March 2015).
- 145 Office for National Statistics (2014) *Mortality statistics: deaths registered in 2013*. ONS: London.
- 146 NHS Wales, Welsh Government (2014) *Together for Health – End-of-life Care Delivery Plan: Annual Report 2014*. NHS Wales/Welsh Government: Cardiff.
- 147 Scottish Partnership for Palliative Care, Marie Curie (2014) *Are we living and dying well yet?* Scottish Partnership for Palliative Care/Marie Curie: Edinburgh.
- 148 Scottish Government. *National indicator on end-of-life care*. Available at: <http://www.gov.scot/About/Performance/scotPerforms/indicator/endoflifecare> (Accessed 11 November 2015).
- 149 Northern Ireland Statistics & Research Agency (2015) *Registrar General Annual Northern Ireland Report 2014*. DfP: Belfast.
- 150 Health and Social Care Board, Public Health Agency (2015) *Commissioning Plan 2014/15*. HSCB/PHA: Belfast. pp.295-296.
- 151 Cox K, Bird L, Arthur A *et al.* "Public attitudes to death and dying in the UK: a review of published literature". *BMJ Support Palliat Care* 2013; **3**: 37–45.

- 152 Shucksmith J, Carlebach S, Whittaker V (2013) *Dying – Discussing and planning for the end of life – British Social Attitudes 30*. NatCen Social Research. Available at: [http://www.bsa.natcen.ac.uk/media/38850/bsa\\_30\\_dying.pdf](http://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf) (Accessed 9 November 2015).
- 153 Chapple A, Evans J, McPherson A *et al.* "Patients with pancreatic cancer and relatives talk about preferred place of death and what influenced their preferences: a qualitative study". *BMJ Support Palliat Care* 2011; doi:10.1136/bmjspcare-2011-000091.
- 154 Cox K, Bird L, Arthur A *et al.* "Public attitudes to death and dying in the UK: a review of published literature". *BMJ Support Palliat Care* 2013; **3**: 37–45.
- 155 Seymour J, Kennedy S, Arthur A *et al.* (2009) *Public attitudes to death, dying and bereavement: a systematic synthesis – Executive summary*. Available at: <http://www.nottingham.ac.uk/research/groups/srcc/documents/projects/srcc-project-summary-public-attitudes.pdf> (Accessed 8 March 2015).
- 156 Shucksmith J, Carlebach S, Whittaker V (2013) *Dying – Discussing and planning for the end of life – British Social Attitudes 30*. NatCen Social Research. Available at: [http://www.bsa.natcen.ac.uk/media/38850/bsa\\_30\\_dying.pdf](http://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf) (Accessed 9 November 2015).
- 157 Sue Ryder, Demos (2013) *A time and a place: what people want at the end of life*. Available at: <http://www.sueryder.org/~media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx> (Accessed 9 March 2015). p.5.
- 158 Marie Curie (2015) *Marie Curie survey highlights top concerns of public when it comes to caring for a terminally ill loved one*. Press release, 2 March 2015. Available at: <http://www2.mariecurie.org.uk/en-GB/Media/Press-releases-and-comments/Marie-Curie-survey-highlights-top-concerns-of-public-when-it-comes-to-caring-for-a-terminally-ill-loved-one/> (Accessed 11 November 2015).
- 159 More information available at: <http://www.dyingmatters.org/> (Accessed 11 November 2015).
- 160 Shucksmith J, Carlebach S, Whittaker V (2013) *Dying – Discussing and planning for the end of life - British Social Attitudes 30*. NatCen Social Research. Available at: [http://www.bsa.natcen.ac.uk/media/38850/bsa\\_30\\_dying.pdf](http://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf) (Accessed 9 November 2015).
- 161 ComRes (2015) *National Council for Palliative Care – Public Opinion on Death and Dying – 29-30 April 2015*. Available at: [http://comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care\\_Public-opinion-on-death-and-dying.pdf](http://comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care_Public-opinion-on-death-and-dying.pdf) (Accessed 25 August 2015).
- 162 Shucksmith J, Carlebach S, Whittaker V (2013) *Dying – Discussing and planning for the end of life - British Social Attitudes 30*. NatCen Social Research. Available at: [http://www.bsa.natcen.ac.uk/media/38850/bsa\\_30\\_dying.pdf](http://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf) (Accessed 9 November 2015).
- 163 ComRes (2015) *National Council for Palliative Care – Public Opinion on Death and Dying – 29-30 April 2015*. Available at: [http://comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care\\_Public-opinion-on-death-and-dying.pdf](http://comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care_Public-opinion-on-death-and-dying.pdf) (Accessed 25 August 2015).
- 164 Marie Curie (2015) *Triggers for palliative care – Improving access to care for people with diseases other than cancer*. Marie Curie: London.
- 165 Gardiner C, Cobb M, Gott M *et al.* "Barriers to providing palliative care for older people in acute hospitals." *Age and Ageing* 2011; **40**: 233-238.
- 166 Mitchell H, Noble S, Finlay I *et al.* "Defining the palliative care patient: its challenges and implications for service delivery". *BMJ Support Palliat Care* 2012; **3**: 46–52.
- 167 Mason B, Epiphaniou E, Nanton V *et al.* "Coordination of care for individuals with advanced progressive conditions: a multi-site ethnographic and serial interview study". *Br J Gen Pract* 2013 Aug; **63**(613): e580-8.
- 168 National Council for Palliative Care, Public Health England, Hospice UK (2015) *National Survey of Patient Activity Data for Specialist Palliative Care Services – MDS Summary Report for the Year 2013-2014*. NCPC/PHE/Hospice UK: London.

- 169 National Council for Palliative Care, Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference *et al.* (2012) *Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives*. NCPC: London. p. 5.
- 170 Marie Curie, Bevan Foundation (2014) *Death and dying in Wales: an analysis of inconsistencies in access to specialist palliative care and hospital activity in the last year of life*. Marie Curie/Bevan Foundation: Cardiff.
- 171 Scottish Partnership for Palliative Care, Marie Curie (2014) *Are we living and dying well yet?* Scottish Partnership for Palliative Care/Marie Curie: Edinburgh.
- 172 NHS Improving Quality (2014) *End-of-life care in heart failure: A framework for implementation*. NHIQ: London.
- 173 Kendrick E (2013) *Getting it Right: Improving End-of-life Care for People with Liver Disease*. NHS National End-of-Life Programme: London.
- 174 MND Scotland (2011) *Motor Neurone Disease: a problem solving approach for general practitioners and allied health professionals*. MND Scotland: Edinburgh.
- 175 National Council for Palliative Care, The Neurological Alliance, NHS End-of-life care Programme (2010) *End-of-life care in long term neurological conditions: A framework for implementation*. NCPC/NA/NHS EoLCP: London.
- 176 Kane M (2012) *My life until the end: dying well with dementia*. Alzheimer's Society: London.
- 177 British Geriatric Society (2014) *Fit for Frailty: Consensus best practice guidance for the care of older people living with frailty in community and outpatient settings*. BGS: London.
- 178 Calanzani N, Koffman J, Higginson IJ (2013) *Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK. Demographic profile and the current state of palliative and end of life care provision*. Marie Curie: London.
- 179 Marie Curie (2015) *Palliative and end of life care for Black, Asian and Minority Ethnic Groups in Scotland: Exploring the Barriers*. Marie Curie: Edinburgh.
- 180 Calanzani N, Koffman J, Higginson IJ (2013) *Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK. Demographic profile and the current state of palliative and end of life care provision*. Marie Curie: London.
- 181 Dixon J, King D, Matosevic T *et al.* (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics, Marie Curie: London.
- 182 Dixon J, King D, Matosevic T *et al.* (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. London School of Economics, Marie Curie: London.
- 183 Calanzani N, Koffman J, Higginson IJ (2013) *Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK. Demographic profile and the current state of palliative and end of life care provision*. Marie Curie: London
- 184 Calanzani N, Koffman J, Higginson IJ (2013) *Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK. Demographic profile and the current state of palliative and end of life care provision*. Marie Curie: London.
- 185 Dixon J, King D, Matosevic T *et al.* (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence. Equity in the Provision of Palliative Care in the UK: Review of Evidence*. Marie Curie: London. p. 57.
- 186 Dixon J, King D, Matosevic T *et al.* (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence. Equity in the Provision of Palliative Care in the UK: Review of Evidence*. Marie Curie: London.
- 187 Marie Curie (2013) *Public Perceptions of Death - Headline findings from a ComRes survey of the public conducted on behalf of Marie Curie Cancer Care*. Available at: [https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/improving-end-of-life-care/marie-curie\\_perceptions-of-death-toplines\\_11-february-2013\\_final.pdf](https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/improving-end-of-life-care/marie-curie_perceptions-of-death-toplines_11-february-2013_final.pdf) (Accessed 11 November 2015).
- 188 ComRes (2013) *Perceptions of death survey – online fieldwork 6th-8th February 2013*. Available at: [http://comres.co.uk/wp-content/themes/comres/poll/Marie\\_Curie\\_Perceptions\\_of\\_Death\\_Data\\_February\\_2013.pdf](http://comres.co.uk/wp-content/themes/comres/poll/Marie_Curie_Perceptions_of_Death_Data_February_2013.pdf) (Accessed 11 November 2015)

- 189 ComRes (2015) *National Council for Palliative Care – Public Opinion on Death and Dying – 29-30 April 2015*. Available at: [http://comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care\\_Public-opinion-on-death-and-dying.pdf](http://comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care_Public-opinion-on-death-and-dying.pdf) (Accessed 11 November 2015).
- 190 Wallace J (2003) *Public awareness of palliative care - Report of the findings of the first national survey in Scotland into public knowledge and understanding of palliative care*. Scottish Partnership for Palliative Care: Edinburgh.
- 191 McIlfatrick S, Hasson F, McLaughlin D *et al*. "Public awareness and attitudes toward palliative care in Northern Ireland". *BMC Palliative Care* 2013; **12**: 34.
- 192 McIlfatrick S, Noble H, McCorry NK *et al*. "Exploring public awareness and perceptions of palliative care: A qualitative study". *Palliat Med* 2014; **28**(3): 273-280.
- 193 Tuffrey-Wijne I, Curfs L, Hollins S "Access to palliative care services by people with learning disabilities: is there equity?" *Advances in Mental Health and Learning Disabilities* 2008; **2**(2): 42-48.
- 194 Read S "Palliative care for people with intellectual disabilities: Pitfalls and potential". *Palliat Med* 2013; **27**(1): 3-4.
- 195 Koffman J, Burke G, Dias A *et al*. "Demographic factors and awareness of palliative care and related services". *Palliat Med* 2007; **21**: 145-153.
- 196 Marie Curie (2013) *Public Perceptions of Death – Headline findings from a ComRes survey of the public conducted on behalf of Marie Curie Cancer Care*. Available at: [https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/improving-end-of-life-care/marie-curie\\_perceptions-of-death-toplines\\_11-february-2013\\_final.pdf](https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/improving-end-of-life-care/marie-curie_perceptions-of-death-toplines_11-february-2013_final.pdf) (Accessed 11 November 2015).
- 197 Public Health Agency (2014) *Survey highlights planning, emotional and communication needs of Palliative Care users*. Press statement, 6 October 2014. Available at: <http://www.publichealth.hscni.net/news/survey-highlights-planning-emotional-and-communication-needs-palliative-care-users> (Accessed 8 December 2015).
- 198 Marie Curie (2013) *Public Perceptions of Death – Headline findings from a ComRes survey of the public conducted on behalf of Marie Curie Cancer Care*. Available at: [https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/improving-end-of-life-care/marie-curie\\_perceptions-of-death-toplines\\_11-february-2013\\_final.pdf](https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/improving-end-of-life-care/marie-curie_perceptions-of-death-toplines_11-february-2013_final.pdf) (Accessed 11 November 2015).
- 199 Palliative Care Cymru Implementation Board (2011) *Dying Well Matters - One Wales: 3 years on (2008 – 2011)*. PCIB: Cardiff.
- 200 Finlay I, Byrne A, Sampson C *et al*. "iWantGreatCare Survey: analysis of free text responses by patients and carers." *BMJ Support Palliat Care* 2012; **2**(Supp 1): A30.
- 201 Jones S, Wynne N (2014) *Listening to Dying People in Wales report - the case for improved patient experience data in Wales*. Marie Curie: Penarth.
- 202 Office for National Statistics (2015) *National Survey of Bereaved People (VOICES), 2014*. ONS: London.
- 203 Office for National Statistics (2015) *National Survey of Bereaved People (VOICES), 2014*. ONS: London.
- 204 Office for National Statistics (2015) *National Survey of Bereaved People (VOICES), 2014*. ONS: London.
- 205 Care Quality Commission (2014) *Frimley Park Hospital NHS Foundation Trust: Frimley Park Hospital Quality Report*. Available at: [http://www.cqc.org.uk/sites/default/files/new\\_reports/AAAA2970.pdf](http://www.cqc.org.uk/sites/default/files/new_reports/AAAA2970.pdf) (Accessed 11 November 2015).
- 206 Further information can be found at: <http://www.ambercarebundle.org/homepage.aspx> (Accessed 11 November 2015).
- 207 Care Quality Commission (2015) *Inequalities and variation in end-of-life care: CQC thematic programme*. CQC: London.
- 208 Neuberger J (2013) *More care less pathway – a review of the Liverpool Care Pathway*. Independent Review of the Liverpool Care Pathway: London.
- 209 Gibbins J, McCoubrie R, Forbes K "Why are newly qualified doctors unprepared to care for patients at the end of life?" *Medical Education* 2011; **45**: 389-399.

- 210 Bowden J, Dempsey K, Boyd K *et al*. "Are newly qualified doctors prepared to provide supportive and end-of-life care? A survey of Foundation Year 1 doctors and consultants". *Journal of the Royal College of Physicians Edinburgh* 2013; **43**(1): 24-8.
- 211 General Medical Council (2015) *Summary of 2014 Medical Schools Annual Return*. GMC: London.
- 212 Taubert M, Noble S, Nelson A "What challenges good palliative care provision out of hours? A qualitative interview study of out-of-hours general practitioners". *BMJ Support Palliat Care* 2011; **1**: 13-18.
- 213 Ingleton C, Gardiner C, Seymour J *et al*. "Exploring the education and training needs among the palliative care workforce". *BMJ Support Palliat Care* 2013; **3**: 207-212.
- 214 Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice*. The Stationery Office: London.
- 215 Hollins S, Tuffrey-Wijne I, Kopper L (2009) *Am I Going to Die?* Books Beyond Words: London.
- 216 *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871.
- 217 Mental Capacity Act 2005, s3.
- 218 *P v Cheshire West and Chester Council* [2014] UKSC 19.
- 219 Fry N. *Letter to MCA-DoLS leads in local authorities and the NHS, 14 January 2015*. Available at: <http://www.cqc.org.uk/sites/default/files/DH-Letter-to-MCA-DoLS-Leads-14-January-2015-FINAL.PDF> (Accessed 31 October 2015).
- 220 British Medical Association (2015) *Deprivation of liberty under the Mental Capacity Act: Key points for health professionals*. BMA: London.
- 221 House of Lords Committee on the Mental Capacity Act 2005 (2014) *Mental Capacity Act 2005: Post-legislative scrutiny – Report*. House of Lords: London.
- 222 Scottish Government (2010) *Adults with Incapacity (Scotland) Act 2000. Code of Practice (third edition) for practitioners authorised to carry out medical treatment or research under part 5 of the Act*. SG/2010/57. Scottish Government: Edinburgh.
- 223 Scottish Executive (2010) *Adults with Incapacity (Scotland) Act 2000. Code of Practice (third edition) for practitioners authorised to carry out medical treatment or research under part 5 of the Act*. SG/2010/57. Scottish Executive: Edinburgh. para 1.9.
- 224 *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819.
- 225 Hindmarch T, Hotopf M, Owen GS "Depression and decision-making capacity for treatment or research: a systematic review". *BMC Medical Ethics* 2013; **14**: 54.
- 226 NHS Choices (2014) *Clinical depression – Overview*. Available at: <https://www.nhs.uk/Conditions/Depression/Pages/Introduction.aspx> (Accessed 13 November 2015).
- 227 Stiefel F, Die Trill M, Berney A *et al*. "Depression in palliative care: a pragmatic report from the Expert Working Group of the European Association for Palliative Care". *Support Care Cancer* 2001; **9**: 477-488.
- 228 World Health Organization (1992) *The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines*. WHO: Geneva.
- 229 American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders: DSM-5*. American Psychiatric Association: Washington DC.
- 230 Alexopoulos GS "Depression in the elderly". *Lancet* 2005; **365**: 1961-70.
- 231 Palsson O, Ostling S, Skoog I "The incidence of first onset depression in a population followed from the age of 70 to 85". *Psychol Med* 2001; **31**: 1159-68.
- 232 Rodda J, Walker Z, Carter J "Depression in older adults". *BMJ* 2011; **343**: d5219.
- 233 Alexopoulos GS "Depression in the elderly". *Lancet* 2005; **365**: 1961-70.
- 234 Rodda J, Walker Z, Carter J "Depression in older adults". *BMJ* 2011; **343**: d5219.
- 235 Rodda J, Walker Z, Carter J "Depression in older adults". *BMJ* 2011; **343**: d5219.
- 236 Alexopoulos GS "Depression in the elderly". *Lancet* 2005; **365**: 1961-70.
- 237 Blazer DG "Depression in late life: review and commentary". *J Gerontol Med Sci* 2003; **58A**: 249-65.

- 238 Thomas A "Depression in older people" in Denning T, Thomas A (eds.) (2013) *Oxford Textbook of Old Age Psychiatry: Second Edition*. Oxford University Press: Oxford.
- 239 Lieberman A "Depression in Parkinson's disease – a review". *Acta Neurological Scandinavia* 2006; **113**: 1-8.
- 240 Rodda J, Walker Z, Carter J. "Depression in older adults". *BMJ* 2011; **343**: 5219.
- 241 Wetherell JL, Petkus AK, McChesney K *et al*. "Older adults are less accurate than younger adults at identifying symptoms of anxiety and depression". *J Nerv Ment Dis* 2009; **197**(8): 623-6.
- 242 Downing LJ, Caprio TV, Lyness JM "Geriatric Psychiatry Review: Differential Diagnosis and Treatment of the 3 D's – Delirium, Dementia, and Depression". *Curr Psychiatry Rep* 2013; **15**: 365.
- 243 Rodda J, Walker Z, Carter J "Depression in older adults". *BMJ* 2011; **343**: d5219.
- 244 Stiles PG, McGarrahan JF "The Geriatric Depression Scale: a comprehensive review". *J Clin Geropsychol* 1998; **4**: 89-110.
- 245 Rodda J, Walker Z, Carter J "Depression in older adults". *BMJ* 2011; **343**: d5219.
- 246 Rodda J, Walker Z, Carter J "Depression in older adults". *BMJ* 2011; **343**: d5219.
- 247 Reynolds CF, Frank E, Perel JM *et al*. "Nortriptyline and Interpersonal Psychotherapy as Maintenance Therapies for Major Recurrent Depression: A Randomized Control Trial in Patients Older than 59 Years." *JAMA* 1999; **281**(1): 39-45.
- 248 Reynolds CF, Frank E, Perel JM *et al*. "Nortriptyline and Interpersonal Psychotherapy as Maintenance Therapies for Major Recurrent Depression: A Randomized Control Trial in Patients Older than 59 Years." *JAMA* 1999; **281**(1): 39-45.
- 249 NHS (2014) *End of life care: coping with a terminal illness*. Available at: <http://www.nhs.uk/Planners/end-of-life-care/Pages/Coping-with-a-terminal-illness.aspx> (Accessed 13 November 2015).
- 250 Hotopf M, Chidgey J, Addington-Hall J *et al*. "Depression in advanced disease: a systematic review Part 1. Prevalence and case finding". *Palliative Med* 2002; **16**: 81-97.
- 251 Rayner L, Lee W, Price A *et al*. "The clinical epidemiology of depression in palliative care and the predictive value of somatic symptoms: Cross-sectional survey with four-week follow up". *Palliative Med* 2011; **25**(3): 229-41.
- 252 Stiefel F, Die Trill M, Berney A *et al*. "Depression in palliative care: a pragmatic report from the Expert Working Group of the European Association for Palliative Care". *Support Care Cancer* 2001; **9**: 477-88.
- 253 Fine RL "Depression, anxiety and delirium in the terminally ill patient". *BUMC Proceedings* 2001; **14**: 130-3.
- 254 Block SD "Assessing and managing depression in the terminally ill patient: ACP-ASIM End of Life Care Consensus Panel: American College of Physicians-American Society of Internal Medicine". *Ann Intern Med* 2000; **132**: 209-218.
- 255 Hotopf M, Chidgey J, Addington-Hall J *et al*. "Depression in advanced disease: a systematic review Part 1. Prevalence and case finding". *Palliat Med* 2002; **16**(2): 81-97.
- 256 Wasteson E, Brenne E, Higginson IJ *et al*. "Depression assessment and classification in palliative cancer patients: a systematic literature review". *Palliative Med* 2009; **23**(8): 739-53.
- 257 Rayner L, Lee W, Price A *et al*. "The clinical epidemiology of depression in palliative care and the predictive value of somatic symptoms: Cross-sectional survey with four-week follow-up". *Palliative Med* 2011; **25**(3): 229-41.
- 258 Block SD "Assessing and managing depression in the terminally ill patient: ACP-ASIM End of Life Care Consensus Panel: American College of Physicians-American Society of Internal Medicine". *Ann Intern Med* 2000; **132**: 209-218.
- 259 Lloyd-Williams M "Difficulties in diagnosing and treating depression in the terminally ill cancer patient". *Postgrad Med J* 2000; **76**: 555-8.
- 260 Sharpe M, Strong V, Allen K *et al*. "Major depression in outpatients attending a regional cancer centre: screening and unmet treatment needs". *Br J Cancer* 2004; **90**: 314-20.

- 261 Kendrick T, Dowrick C, McBride A *et al*. "Management of depression in UK general  
practice in relation to scores on depression severity questionnaires: analysis of  
262 medical record data." *BMJ* 2009; **338**: b750.
- 263 Lloyd-Williams M "Difficulties in diagnosing and treating depression in the  
terminally ill cancer patient." *Postgrad Med J* 2000; **76**: 555-8.
- 264 Block SD "Assessing and managing depression in the terminally ill patient: ACP-  
ASIM End of Life Care Consensus Panel: American College of Physicians-American  
265 Society of Internal Medicine". *Ann Intern Med* 2000; **132**: 209-218.
- 266 Lloyd-Williams M "Difficulties in diagnosing and treating depression in the  
terminally ill cancer patient." *Postgrad Med J* 2000; **76**: 555-8.
- 267 Maguire P "Improving the recognition of concerns and affective disorders in  
cancer patients". *Ann Oncol* 2002; **13**(Suppl 4): 177-81.
- 268 Maguire P, Faulkner A, Booth K "Helping cancer patients disclose their concerns".  
*Eur J Cancer* 1996; **32A**: 78-81.
- 269 Delgado-Guay MO and Bruera E "Multi-dimensional patient assessment" in Bruera  
E, Higginson I, von Gunten CF *et al* (eds) (2015). *Textbook of Palliative Medicine  
and Supportive Care, Second Edition*. CRC Press: Boca Raton.
- 270 Tsai JL, Chentsova-Dutton Y "Understanding Depression across Cultures" in Gotlib  
IH, Hammen CL (eds) (2010) *Handbook of Depression – Second Edition*. Guilford  
Press: New York. pp.467-91.
- 271 Baider L "Cultural diversity: family path through terminal illness." *Ann Oncol* 2012;  
**23** (Supplement 3): iii62-iii65.
- 272 Rayner L, Price A, Hotopf M *et al*. "Expert opinion on detecting and treating  
depression in palliative care: A Delphi study". *BMC Palliative Care* 2011;  
**10**: 10-18. p. 10.
- 273 Wasteson E, Brenne E, Higginson IJ *et al*. "Depression assessment and  
classification in palliative cancer patients: a systematic literature review".  
*Palliative Med* 2009; **23**(8): 739-53.
- 274 Rayner L, Price A, Hotopf M *et al*. "Expert opinion on detecting and treating  
depression in palliative care: A Delphi study". *BMC Palliative Care* 2011; **10**: 10-18.
- 275 Lloyd-Williams M, Payne S "A qualitative study of clinical nurse specialists' views  
on depression in palliative care patients". *Palliat Med* 2003; **17**(4): 334-8.
- 276 Rayner L, Higginson IJ, Price A *et al*. (2010) *The Management of Depression in  
Palliative Care: European Clinical Guidelines*. Department of Palliative Care, Policy  
& Rehabilitation/European Palliative Care Research Collaborative: London
- 277 Temel JS, Greer JA, Muzikansky A *et al*. "Early palliative care for patients with  
metastatic non-small-cell lung cancer". *New Eng J Med* 2010; **363**: 733-42.
- 278 Rayner L, Price A, Hotopf M *et al*. "The development of evidence-based European  
guidelines on the management of depression in palliative cancer care". *Eur J  
Cancer* 2011; **47**: 702-12.
- 279 Lloyd-Williams M, Shiels C, Dowrick C "The development of the Brief Edinburgh  
Depression Scale (BEDS) to screen for depression in patients with advanced  
cancer". *Journal of Affective Disorders* 2007; **99**(1-3): 259-264.
- 280 Ly KL, Chidgey J, Addington-Hall J *et al*. "Depression in palliative care: a systematic  
review. Part 2. Treatment. *Palliative Med* 2002; **16**: 279-284.
- 281 National Institute for Health and Care Excellence (2009) *Depression in adults:  
Recognition and management (CG90)*. NICE: London.
- 282 Rayner L, Lee W, Price A *et al*. "The clinical epidemiology of depression in palliative  
care and the predictive value of somatic symptoms: Cross-sectional survey with  
four-week follow-up". *Palliative Med* 2011; **25**(3): 229-41.
- 283 Rayner L, Higginson IJ, Price A *et al*. (2010) *The Management of Depression in  
Palliative Care: European Clinical Guidelines*. Department of Palliative Care, Policy  
& Rehabilitation/European Palliative Care Research Collaborative: London. p.19.
- 284 Rayner L, Price A, Hotopf M *et al*. "The development of evidence-based European  
guidelines on the management of depression in palliative cancer care". *Eur J  
Cancer* 2011; **47**: 201-12.
- 285 Block SD "Assessing and managing depression in the terminally ill patient: ACP-  
ASIM End of Life Care Consensus Panel: American College of Physicians-American  
Society of Internal Medicine". *Ann Intern Med* 2000; **132**: 209-218.

- 284 Sharpe M, Walker J, Holm Hansen C *et al.* "Integrated collaborative care for comorbid major depression in patients with cancer (SMaRT Oncology-2): a multicentre randomised controlled effectiveness trial". *Lancet* 2014; **384**: 1099-1108.
- 285 Ly KL, Chidgey J, Addington-Hall J *et al.* "Depression in palliative care: a systematic review. Part 2. Treatment". *Palliative Med* 2002; **16**: 279-84.
- 286 Lloyd-Williams M, Friedman T, Rudd M "A survey of antidepressant prescribing in the terminally ill". *Palliative Med* 1999; **13**(3): 243-8.
- 287 Block SD "Assessing and managing depression in the terminally ill patient: ACP-ASIM End of Life Care Consensus Panel: American College of Physicians-American Society of Internal Medicine". *Ann Intern Med* 2000; **132**: 209-218.
- 288 Rayner L, Price A, Evans A *et al.* "Antidepressants for the treatment of depression in palliative care: systematic review and meta-analysis". *Palliative Med* 2011; **25**(1): 36-51.
- 289 Rayner L, Price A, Evans A *et al.* "Antidepressants for the treatment of depression in palliative care: systematic review and meta-analysis". *Palliative Med* 2011; **25**(1): 36-51.
- 290 Korff MV, Simon G "The Relationship Between Pain and Depression." *BJ Psych* 1996; **168**(s30): 101-108.
- 291 Rayner L, Lee W, Price A *et al.* "The clinical epidemiology of depression in palliative care and the predictive value of somatic symptoms: Cross-sectional survey with four-week follow up". *Palliative Med* 2011; **25**(3): 229-41.
- 292 Bair MJ, Robinson RL, Katon W *et al.* "Depression and Pain Comorbidity: A Literature Review" *Arch Intern Med* 2003; **163**(20): 2433-45.
- 293 Strang P "Cancer pain – a provoker of emotional, social, and existential distress." *Acta Oncol* 1998; **37**(7-8): 641-44.
- 294 Block SD "Assessing and managing depression in the terminally ill patient: ACP-ASIM End of Life Care Consensus Panel: American College of Physicians-American Society of Internal Medicine". *Ann Intern Med* 2000; **132**: 209-218.
- 295 Chochinov HM, Wilson KG, Enns M *et al.* "Desire for death in the terminally ill". *Am J Psychiatry* 1995; **152**(8): 1885-91.
- 296 Price A, Lee W, Goodwin L *et al.* "Prevalence, course and associations of desire for hastened death in a UK palliative population: a cross-sectional study". *BMJ Supportive & Palliative Care* 2011; **1**(2): 140-148.
- 297 Breitbart W, Rosenfeld B, Pessin H *et al.* "Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer". *JAMA* 2000; **284**(22): 2907-11.
- 298 Breitbart W, Rosenfeld B, Pessin H *et al.* "Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer." *JAMA* 2000; **284**(22): 2907-2911.
- 299 Rayner L, Lee W, Price A *et al.* "The clinical epidemiology of depression in palliative care and the predictive value of somatic symptoms: Cross-sectional survey with four-week follow up". *Palliative Med* 2011; **25**(3): 229-41.
- 300 Rodin G, Lo C, Mikulincer M *et al.* "Pathways to distress: the multiple determinants of depression, hopelessness, and the desire for hastened death in metastatic cancer patients." *Soc Sci Med* 2009; **68**(3): 562-9.
- 301 Mystakidou K, Rosenfeld B, Parpa E *et al.* "Desire for death near the end of life: the role of depression, anxiety and pain". *Gen Hosp Psychiatry* 2005; **27**(4): 258-62.
- 302 O'Mahony S, Goulet J, Kornblith A *et al.* "Desire for hastened death, cancer pain and depression: report of a longitudinal observational study." *J Pain Symptom Manage* 2005; **29**(5): 446-57.
- 303 Price A, Lee W, Goodwin L *et al.* "Prevalence, course and associations of desire for hastened death in a UK palliative population: a cross-sectional study". *BMJ Supportive and Palliative Care* 2011; **1**(2): 140-8.
- 304 Ganzini L, Lee MA, Heintz RT *et al.* "The effect of depression treatment on elderly patients' preferences for life-sustaining medical therapy". *Am J Psychiatry* 1994; **151**(11): 1631-6.



- 305 Breitbart W, Rosenfeld B, Gibson C *et al*. "Impact of treatment for depression on  
desire for hastened death in patients with advanced AIDS". *Psychosomatics* 2010;  
**51**(2): 98-105.
- 306 The Shipman Inquiry, UK Government Web Archive. Available at: <http://webarchive.nationalarchives.gov.uk/20090808154959/http://www.the-shipman-inquiry.org.uk/reports.asp> (Accessed 8 December 2015).
- 307 The Shipman Inquiry, *Fourth report – The regulation of controlled drugs in the community* (July 2004) UK Government Web Archive. Available at: <http://webarchive.nationalarchives.gov.uk/20090808154959/http://www.the-shipman-inquiry.org.uk/fourthreport.asp> (Accessed 8 December 2015).
- 308 The Shipman Inquiry, *Fifth Report - Safeguarding Patients: Lessons from the Past - Proposals for the Future*, (December 2004), UK Government Web Archive. Available at: <http://webarchive.nationalarchives.gov.uk/20090808154959/http://www.the-shipman-inquiry.org.uk/fifthreport.asp> (Accessed 8 December 2015).
- 309 General Medical Council (2013) *An introduction to revalidation*. Available at: <http://www.gmc-uk.org/doctors/revalidation/9627.asp> (Accessed 8 December 2015).
- 310 HM Government (2004) *Safer management of controlled drugs: The Government's response to the fourth report of the Shipman Inquiry*. HMSO: Norwich.
- 311 Controlled Drugs (Supervision of Management and Use) Regulations 2006 (subsequently replaced by the Controlled Drugs (Supervision of Management and Use) Regulations 2013).
- 312 Care Quality Commission (2015) *Controlled Drugs*. Available at: <http://www.cqc.org.uk/content/controlled-drugs> (Accessed 8 December 2015).
- 313 Pommert K "'Shipman effect' harms pain care". *BBC News Online*, Monday 7 August 2006. Available at: <http://news.bbc.co.uk/1/hi/health/5252902.stm> (Accessed 18 November 2015).
- 314 Queiro A "Shipman effect: How a serial killer changed medical practice forever". *BBC News Scotland*, 1 December 2014. Available at: <http://www.bbc.co.uk/news/uk-scotland-30192721> (Accessed 18 November 2015).
- 315 "The UK General Election: a manifesto for health". *Lancet* 2015; 385(9971): 829.
- 316 Fohr SA "The double effect of pain medication: separating myth from reality". *Journal of Palliative Medicine* 1998; **1**(4): 315-28.
- 317 Sykes N, Thorns A "Sedative use in the last week of life and the implications for end-of-life decision making". *Arch Intern Med* 2003; **163**(3): 341-4.
- 318 Sykes N, Thorns A "The use of opioids and sedatives at the end of life" *Lancet Oncology* 2003; **4**(5): 312-8.
- 319 British Medical Association Ethics Department. (2012) *Medical Ethics Today: The BMA's Handbook of Ethics and Law*, Third Edition. Wiley-Blackwell/BMJ Books: London. p.435.
- 320 Dyer C "Court confirms right to palliative treatment for mental distress". *BMJ* 2007; **315**: 1177.
- 321 Fohr SA "The double effect of pain medication: separating myth from reality". *Journal of Palliative Medicine* 1998; **1**(4): 315-28.
- 322 Sykes N, Thorns A "The use of opioids and sedatives at the end of life" *Lancet Oncology* 2003; **4**(5): 312-8.
- 323 General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*. GMC: London, para 26.
- 324 General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*. GMC: London, para 34.
- 325 Hicks F "Post-Shipman: the impact on developing education in cancer and palliative care pain management" in Foyle L, Hostad J (eds.) (2014) *Delivering Cancer and Palliative Care Education*. CRC Press: Boca Raton. pp.61-71, p.69.
- 326 Duffin C "GPs 'failing to manage pain post-Shipman.'" *Pulse*, 16 May 2011. Available at: <http://www.pulsetoday.co.uk/gps-failing-to-manage-pain-post-shipman/12201476.article#.VRPqOvmsVps> (Accessed 18 November 2015).

- 327 Finch R "Shipman has made GPs wary of prescribing strong opioids". *Pulse*, 18 April 2004. Available at: <http://www.pulsetoday.co.uk/shipman-has-made-gps-wary-of-prescribing-strong-opioids/10885147.fullarticle> (Accessed 18 November 2015).
- 328 "Shipman effect 'alters GP habits'". *BBC News Online*, 8 August 2006. Available at <http://news.bbc.co.uk/1/hi/health/5254878.stm> (Accessed 18 November 2015).
- 329 Gao W, Gulliford M, Higginson IJ "Prescription patterns of analgesics in the last 3 months of life: a retrospective analysis of 10 202 lung cancer patients". *Br J Cancer* 2011; **104**: 1704-10.
- 330 Gao W, Gulliford M, Bennett MI *et al*. "Managing Cancer Pain at the End of Life with Multiple Strong Opioids: A Population-Based Retrospective Cohort Study in Primary Care". *PLoS One* 2014; **9**(1): e79266.
- 331 Zin CS, Chen LC, Knaggs RD "Changes in trends and pattern of strong opioid prescribing in primary care". *Eur J Pain* 2014; **18**: 1343 – 51.
- 332 Gardiner C, Gott M, Ingleton C *et al*. "Attitudes of Health Care Professionals to Opioid Prescribing in End-of-Life Care: A Qualitative Focus Group Survey". *J Pain Symp Manage* 2012; **44**(2): 206-14.
- 333 Glare P, Virik K, Jones M *et al*. "A systematic review of physicians' survival predictions in terminally ill cancer patients." *BMJ* 2003; **327**: 195.
- 334 Higginson I, Massimo C "Accuracy of prognosis estimates by four palliative care teams: a prospective cohort study." *BMC Palliative Care* 2002; **1**(1): 1-5.
- 335 Selby D, Chakraborty A, Lilien T *et al*. "Clinician accuracy when estimating survival duration: the role of the patient's performance status and time-based prognostic categories." *J Pain Symp Manage* 2011; **42**(4): 578-588.
- 336 Christakis NA, Lamont EB "Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study." *BMJ* 2000; **320**: 469-473.
- 337 Hui D, Kilgore K, Nguyen L *et al*. "The accuracy of probabilistic versus temporal clinician prediction of survival for patients with advanced cancer: a preliminary report." *The Oncologist* 2011; **16**(11): 1642-1648.
- 338 Perez-Cruz PE, Dos Santos R, Buosi Silva T *et al*. "Longitudinal temporal and probabilistic prediction of survival in a cohort of patients with advanced cancer." *J Pain Symp Manage* 2014; **48**(5): 875-882.
- 339 Lau F, Cloutier-Fisher D, Kuziemy C *et al*. "A Systematic Review of Prognostic Tools for Estimating Survival Time." *Journal of Palliative Care* 2007; **23**(2): 93-112.
- 340 Maltoni M, Nanni O, Pirovano M *et al*. "Successful validation of the palliative prognostic score in terminally ill cancer patients." *J Pain Symp Manage* 1999; **17**(4): 240-247.
- 341 Glare P, Eychmueller S, McMahon P "Diagnostic accuracy of the palliative prognostic score in hospitalized patients with advanced cancer". *J Clin Oncol* 2004; **22**(23): 4823-4828.
- 342 Glare P, Eychmueller S, Virik K "The use of the palliative prognostic score in patients with diagnoses other than cancer." *J Pain Symp Manage* 2003; **26**(4): 883-885.
- 343 Naylor C, Cerquerira L, Costa-Paiva LHS *et al*. "Survival of women with cancer in palliative care: use of the palliative prognostic score in a population of Brazilian women." *J Pain Symp Manage* 2010; **39**(1): 69-75.
- 344 Tarumi Y, Watanabe SM, Lau F *et al*. "Evaluation of the Palliative Prognostic Score (PaP) and routinely collected clinical data in prognostication of survival for patients referred to a palliative care consultation service in an acute care hospital." *J Pain Symp Manage* 2011; **42**(3): 419-431.
- 345 Numico G, Occelli M, Russ EG *et al*. "Survival prediction and frequency of anticancer treatment in cancer patients hospitalized due to acute conditions. Role of clinical parameters and PaP score." *Support Care Cancer* 2011; **19**(11): 1823-1830.
- 346 Glare P, Virik K "Independent prospective validation of the PaP score in terminally ill patients referred to a hospital-based palliative medicine consultation service." *J Pain Symp Manage* 2001; **22**(5): 891-898.

- 347 Sonoda H, Yamaguchi T, Matsumoto M *et al.* "Validation of the Palliative Prognostic Index and Palliative Prognostic Score in a palliative care consultation team setting for patients with advanced cancers in an acute care hospital in Japan." *Am J Hosp Palliat Care* 2007; **31**(7): 730-734.
- 348 Glare P, Virik K "Independent prospective validation of the PaP score in terminally ill patients referred to a hospital-based palliative medicine consultation service." *J Pain Symp Manage* 2001; **22**(5): 891-8.
- 349 Naylor C, Cerquerira L, Costa-Paiva LHS *et al.* "Survival of women with cancer in palliative care: use of the palliative prognostic score in a population of Brazilian women." *J Pain Symp Manage* 2010; **39**(1): 69-75.
- 350 Glare P, Virik K "Independent prospective validation of the PaP score in terminally ill patients referred to a hospital-based palliative medicine consultation service." *J Pain Symp Manage* 2001; **22**(5): 891-898.
- 351 Stone PC, Lund S "Predicting prognosis in patients with advanced cancer." *Ann Oncol* 2007; **18**(6): 971-976.
- 352 Maltoni M, Scarpi E, Pittureri C *et al.* "Prospective comparison of prognostic scores in palliative care cancer populations." *The Oncologist* 2012; **17**(3): 446-454.
- 353 Morita T, Tsunoda J, Inoue S *et al.* "The Palliative Prognostic Index: a scoring system for survival prediction of terminally ill cancer patients." *Support Care Cancer* 1999; **7**(3): 128-133.
- 354 Morita T, Tsunoda J, Inoue S *et al.* "Improved accuracy of physicians' survival prediction for terminally ill cancer patients using the Palliative Prognostic Index." *Palliat Med* 2001; **15**(5): 419-424.
- 355 Morita T, Tsunoda J, Inoue S *et al.* "Improved accuracy of physicians' survival prediction for terminally ill cancer patients using the Palliative Prognostic Index." *Palliat Med* 2001; **15**(5): 419-424.
- 356 Maltoni M, Scarpi E, Pittureri C *et al.* "Prospective comparison of prognostic scores in palliative care cancer populations." *The Oncologist* 2012; **17**(3): 446-454.
- 357 Gwilliam B, Vaughan K, Todd C *et al.* "Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study." *BMJ* 2011; **343**: d4920.
- 358 Lee DS, Austin PC, Rouleau JL *et al.* "Predicting mortality among patients hospitalized for heart failure: derivation and validation of a clinical model." *JAMA* 2003; **290**(19): 2581-2587.
- 359 Haga K, Murray S, Reid J *et al.* "Identifying community based chronic heart failure patients in the last year of life: a comparison of the Gold Standards Framework Prognostic Indicator Guide and the Seattle Heart Failure Model." *Heart* 2012; **98**(7): 579-583.
- 360 Murray SA, Kendall M, Boyd K *et al.* "Illness trajectories and palliative care." *BMJ* 2005; **330**: 1007.
- 361 British Medical Association (2015) *Responding to patient requests relating to assisted suicide: guidance for doctors in England, Wales and Northern Ireland*. Available at: <http://bma.org.uk/practical-support-at-work/ethics/ethics-a-to-z> (Accessed 9 December 2015).
- 362 General Medical Council (2013) *When a patient seeks advice or information about assistance to die*. GMC: London.
- 363 BBC News Online. "Husband's tribute to Diane Pretty". *BBC News Online*, Monday 13 May 2002. Available at: <http://news.bbc.co.uk/1/hi/health/1983941.stm> (Accessed 18 November 2015).
- 364 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2001] UKHL 61.
- 365 *Pretty v United Kingdom* (2346/02) 35 EHRR 1, at 40.
- 366 *Pretty v United Kingdom* (2346/02) 35 EHRR 1, at 67.
- 367 *Pretty v United Kingdom* (2346/02) 35 EHRR 1, at 78.
- 368 *R (on the application of Purdy) v Director of Public Prosecutions* [2009] UKHL 45.
- 369 *R (on the application of Purdy) v Director of Public Prosecutions* [2009] UKHL 45, at 40.
- 370 *R (on the application of Purdy) v Director of Public Prosecutions* [2009] UKHL 45, at 102.

- 371 Tran M. "Assisted suicide campaigner Debbie Purdy dies aged 51". *The Guardian*, 29 December 2014. Available at: <http://www.theguardian.com/society/2014/dec/29/assisted-suicide-campaigner-debbie-purdy-dies> (Accessed 18 November 2015).
- 372 Director of Public Prosecutions (2010, updated October 2014) *Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide*. Available at: [http://www.cps.gov.uk/publications/prosecution/assisted\\_suicide.html](http://www.cps.gov.uk/publications/prosecution/assisted_suicide.html) (Accessed 18 November 2015).
- 373 A full list of published decisions, updated every six months, can be found at: [https://www.cps.gov.uk/publications/prosecution/assisted\\_suicide.html](https://www.cps.gov.uk/publications/prosecution/assisted_suicide.html) (Accessed 18 November 2015).
- 374 Director of Public Prosecutions Press Release (12 September 2013) "Kevin Howe convicted of assisted suicide attempt". Available at: [http://www.cps.gov.uk/news/latest\\_news/kevin\\_howe\\_convicted\\_of\\_assisted\\_attempted\\_suicide/](http://www.cps.gov.uk/news/latest_news/kevin_howe_convicted_of_assisted_attempted_suicide/) (Accessed 18 November 2015).
- 375 The DPP's policy can be found, in full, at: [https://www.cps.gov.uk/publications/prosecution/assisted\\_suicide\\_policy.html](https://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html) (Accessed 18 November 2015).
- 376 *R (on the application of Nicklinson and another) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions* [2014] UKSC 38.
- 377 *R (on the application of Nicklinson and another) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions* [2014] UKSC 38, at 230.
- 378 *R (on the application of Nicklinson and another) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions* [2014] UKSC 38, at 118, 190, 197.
- 379 *R (on the application of Nicklinson and another) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions* [2014] UKSC 38, at 118.
- 380 *Nicklinson and Lamb v the United Kingdom* (2015), 2478/15 and 1787/15, at 86.
- 381 *Nicklinson and Lamb v the United Kingdom* (2015), 2478/15 and 1787/15, at 84.
- 382 *Nicklinson and Lamb v the United Kingdom* (2015), 2478/15 and 1787/15, at 94.
- 383 *R (on the application of Nicklinson and another) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions* [2014] UKSC 38.
- 384 *R (on the application of Nicklinson and another) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions* [2014] UKSC 38, at 249.
- 385 *R (on the application of Nicklinson and another) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions* [2014] UKSC 38, at 148.
- 386 Director of Public Prosecutions (2010, updated October 2014) *Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide*. Available at [http://www.cps.gov.uk/publications/prosecution/assisted\\_suicide.html](http://www.cps.gov.uk/publications/prosecution/assisted_suicide.html) (Accessed 18 November 2015).
- 387 Doughty S "Doctors and nurses who help terminally ill patients to die will be LESS likely to be prosecuted under new guidelines for assisted suicide". *Daily Mail Online*, 17 October 2014. Available at: <http://www.dailymail.co.uk/news/article-2796553/rules-eased-doctors-help-sick-die-director-public-prosecutions-says-laws-state-healthcare-professionals-prosecuted-helping-patients-commit-suicide-wrong.html> (Accessed 18 November 2015).
- 388 Bingham J "Assisted suicide guidelines relaxed by Director of Public Prosecutions" *The Telegraph*, 16 October 2014. Available at <http://www.telegraph.co.uk/news/health/11168519/Assisted-suicide-guidelines-relaxed-by-Director-of-Public-Prosecutions.html> (Accessed 9 December 2015).
- 389 Crown Prosecution Service. *Director of Public Prosecutions responds to Supreme Court on assisted suicide policy*. CPS Press Release, 16 October 2014. Available at [http://www.cps.gov.uk/news/latest\\_news/director\\_of\\_public\\_prosecutions\\_responds\\_to\\_supreme\\_court\\_on\\_assisted\\_suicide\\_policy/](http://www.cps.gov.uk/news/latest_news/director_of_public_prosecutions_responds_to_supreme_court_on_assisted_suicide_policy/) (Accessed 9 December 2015).
- 390 General Medical Council (2015) *When a patient seeks advice or information about assistance to die*. GMC: London.
- 391 *R (on the application of AM) v The General Medical Council* [2015] EWHC 2096 (Admin) at 42.

- 392 *R (on the application of AM) v The General Medical Council* [2015] EWHC 2096  
(Admin) at 52.
- 393 Lord Advocate, Frank Mulholland, Written evidence on the Assisted Suicide  
(Scotland) Bill (ASB 178). Available at: [http://www.scottish.parliament.uk/  
parliamentarybusiness/CurrentCommittees/79563.aspx](http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/79563.aspx) (Accessed 18 November  
2015).
- 394 Crown Office and Procurator Fiscal Service (2001) *Prosecution Code*. COPFS:  
Edinburgh.
- 395 'No guidance' on assisted suicide". *BBC News Online*, 23 September 2009.  
Available at <http://news.bbc.co.uk/1/hi/scotland/8271869.stm> (Accessed 18  
November 2015).
- 396 Scottish Parliament Health and Sport Committee (2015) *6<sup>th</sup> Report, 2015, Stage  
1 Report on the Assisted Suicide (Scotland) Bill (Revised)*. Scottish Parliament:  
Edinburgh, para 24.
- 397 Scottish Parliament (2015) *Official Report: Health and Sport Committee, Tuesday  
13 January 2015. Session 4*. Scottish Parliament: Edinburgh. p.8.
- 398 *Opinion of Lord Doherty in the petition of Gordon Ross* [2015] CSOH 123.
- 399 *Opinion of Lord Doherty in the petition of Gordon Ross* [2015] CSOH 123.
- 400 *Opinion of Lord Doherty in the petition of Gordon Ross* [2015] CSOH 123, at para 44.
- 401 *Opinion of Lord Doherty in the petition of Gordon Ross* [2015] CSOH 123, at para 45.
- 402 Puttick H "Grandfather seeking the right to die loses legal battle for assisted  
suicide guidance to be published". *The Herald*, Tuesday 8 September 2015.  
Available at: [http://www.heraldscotland.com/news/13652474.Grandfather  
seeking\\_the\\_right\\_to\\_die\\_loses\\_legal\\_battle\\_for\\_assisted\\_suicide\\_guidance  
to\\_be\\_published/](http://www.heraldscotland.com/news/13652474.Grandfather<br/>seeking_the_right_to_die_loses_legal_battle_for_assisted_suicide_guidance<br/>to_be_published/) (Accessed 18 November 2015).
- 403 Public Prosecution Service for Northern Ireland (2010) *Policy on Prosecuting  
the Offence of Assisted Suicide*. Available at: [http://www.ppsni.gov.uk/  
SiteDocuments/PPS%20Press%20Office/Policy%20on%20Prosecuting%20  
the%20Offence%20of%20Assisted%20Suicide.pdf](http://www.ppsni.gov.uk/<br/>SiteDocuments/PPS%20Press%20Office/Policy%20on%20Prosecuting%20<br/>the%20Offence%20of%20Assisted%20Suicide.pdf) (Accessed 18 November  
2015).
- 404 House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill  
(2005) *The Report of the House of Lords Select Committee on the Assisted Dying  
for the Terminally Ill Bill*. The Stationery Office: London.
- 405 House of Lords Hansard, 12 May 2006, col. 1184.
- 406 In light of the stated aims of the Commission, and the BMA's policy of opposition  
to assisted dying, it was agreed that it would be inappropriate for the BMA  
to engage with the Commission by giving oral evidence or detailed written  
comment.
- 407 Commission on Assisted Dying (2012) *'The current legal status of assisted dying is  
inadequate and incoherent...'* Demos: London. p. 38.
- 408 Commission on Assisted Dying (2012) *'The current legal status of assisted dying is  
inadequate and incoherent...'* Demos: London.
- 409 House of Lords Hansard, 18 July 2014, col. 775.
- 410 House of Lords Hansard, 7 November 2014, Vol 756, No 54.
- 411 House of Lords Hansard, 7 November 2014, Vol 756, No 54.
- 412 House of Lords Hansard 16 January 2015, Vol 758, No 86.
- 413 House of Commons Hansard, 11 September 2015, col. 656.
- 414 Assisted Dying (No 2) Bill 2015-16. Available at: [http://services.parliament.uk/  
bills/2015-16/assisteddyingno2.html](http://services.parliament.uk/<br/>bills/2015-16/assisteddyingno2.html) (Accessed 9 December 2015).
- 415 House of Commons Hansard, 11 September 2015, Vol 599, No 42.
- 416 Martin S. "Colombian Physicians Get the Final Go-Ahead for Euthanasia".  
*Pan Am Post*, 23 April 2015. Available at: [http://panampost.com/sabrina-  
martin/2015/04/23/colombian-physicians-get-the-final-go-ahead-for-  
euthanasia/](http://panampost.com/sabrina-<br/>martin/2015/04/23/colombian-physicians-get-the-final-go-ahead-for-<br/>euthanasia/) (Accessed 18 November 2015).
- 417 Commission on Assisted Dying (2012) *'The current legal status of assisted dying is  
inadequate and incoherent...'* Demos: London. pp.310-11.
- 418 House of Lords Hansard, 7 November 2014, Vol 756.

- 419 Right to Die for the Terminally Ill Bill 2005. Available at: <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/21672.aspx> (Accessed 18 November 2015).
- 420 End of Life Assistance (Scotland) Bill 2009. Available at: <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/21272.aspx> (Accessed 18 November 2015).
- 421 Assisted Suicide (Scotland) Bill 2013. Available at: <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/69604.aspx> (Accessed 9 December 2015).
- 422 Scottish Parliament Health and Sport Committee (2015) *6<sup>th</sup> Report, 2015, Stage 1 Report on the Assisted Suicide (Scotland) Bill (Revised)*. Scottish Parliament: Edinburgh, para 24.
- 423 Scottish Parliament Minutes of Proceedings: Parliamentary Year 5, No. 8 Session 4. Wednesday 27 May 2015.
- 424 Seale C "Legalisation of euthanasia or physician-assisted suicide: survey of doctors' attitudes." *Palliat Med* 2009; **23**(3): 205-12.
- 425 McCormack R, Clifford M, Conroy M "Attitudes of UK doctors towards euthanasia and physician-assisted suicide: a systematic literature review." *Palliat Med* 2012; **26**(1): 23-33.
- 426 Lee W, Price A, Rayner L *et al*. "Survey of doctors' opinions of the legalization of physician-assisted suicide." *BMC Medical Ethics* 2009; **10**: 2.
- 427 Pasterfield D, Wilkinson C, Finlay IG *et al*. "GPs' views on changing the law on physician-assisted suicide and euthanasia, and willingness to prescribe or inject lethal drugs: a survey from Wales." *Br J Gen Pract* 2006 Jun; **56**(527): 450-2.
- 428 Seale C "Legalisation of euthanasia or physician-assisted suicide: survey of doctors' attitudes." *Palliat Med* 2009; **23**(3): 205-12.
- 429 McCormack R, Clifford M, Conroy M *et al*. "Attitudes of UK doctors towards euthanasia and physician-assisted suicide: a systematic literature review." *Palliat Med* 2012; **26**(1): 23-33.
- 430 Lee W, Price A, Rayner L *et al*. "Survey of doctors' opinions of the legalization of physician-assisted suicide." *BMC Medical Ethics* 2009; **10**: 2.
- 431 Seale C "Legalisation of euthanasia or physician-assisted suicide: survey of doctors' attitudes." *Palliat Med* 2009; **23**(3): 205-12.
- 432 Kitching M, Stevens AJ, Forman L *et al*. "Views regarding physician-assisted suicide: A study of medical professionals at various points in their training." *Clinical Ethics* 2008; **3**(1): 27-33.
- 433 Kitching M, Stevens AJ, Forman L *et al*. "Views regarding physician-assisted suicide: A study of medical professionals at various points in their training." *Clinical Ethics* 2008; **3**(1): 27-33.
- 434 Seale C "Legalisation of euthanasia or physician-assisted suicide: survey of doctors' attitudes." *Palliat Med* 2009; **23**(3): 205-12.
- 435 Pasterfield D, Wilkinson C, Finlay IG *et al*. "GPs' views on changing the law on physician-assisted suicide and euthanasia, and willingness to prescribe or inject lethal drugs: a survey from Wales." *Br J Gen Pract* 2006 Jun; **56**(527): 450-2.
- 436 Shah N, Warner J, Blizard B *et al*. "National survey of UK psychiatrists' attitudes to euthanasia." *Lancet* 2008; **352**: 1360.
- 437 Kitching M, Stevens AJ, Forman L *et al*. "Views regarding physician-assisted suicide: A study of medical professionals at various points in their training." *Clinical Ethics* 2008; **3**(1): 27-33.
- 438 Medix (2014) "Euthanasia & Physician-assisted-suicide – a summary of results". Available at: <http://medixglobal.com/Medix-Case-Study-18-Euthanasia-and-Physician-assisted-Suicide.pdf> (Accessed 9 December 2015).
- 439 Health Care Professionals for Assisted Dying. "Patients would trust doctors more if assisted dying was legal". HPAD Press Release, 1 June 2015. Available at: <http://www.hpad.org.uk/press-release/patients-trust-doctors-assisted-dying/> (Accessed 28 September 2015).
- 440 Dignity in Dying (2014) "New poll finds the majority of GPs would like the choice of assisted dying to be available to them or did not discount it." Available at: <http://www.dignityindying.org/uk/press-release/new-poll-finds-majority-gps-like-choice-assisted-dying-available-discount/> (Accessed 30 September 2015).

- 441 Health Care Professionals for Assisted Dying. "Patients would trust doctors more if assisted dying was legal". HPAD Press Release, 1 June 2015. Available at: <http://www.hpad.org.uk/press-release/patients-trust-doctors-assisted-dying/> (Accessed 28 September 2015).
- 442 Dignity in Dying (2014) "New poll finds the majority of GPs would like the choice of assisted dying to be available to them or did not discount it". Available at: <http://www.dignityindying.org.uk/press-release/new-poll-finds-majority-gps-like-choice-assisted-dying-available-discount/> (Accessed 11 March 2015).
- 443 British Medical Association (2012) *What is current BMA policy on assisted dying?* Available at: <http://bma.org.uk/support-at-work/ethics/bma-policy-assisted-dying> (Accessed 16 November 2015).
- 444 Royal College of General Practitioners (2014) "RCGP announces continued opposition to change in law on assisted dying." Press release February 21 2014. Available at: <http://www.rcgp.org.uk/news/2014/february/rcgp-remains-opposed-to-any-change-in-the-law-on-assisted-dying.aspx> (accessed 11 March 2015).
- 445 Royal College of General Practitioners (2014) *Assisted Dying Consultation Analysis*. Available at: <http://www.rcgp.org.uk/policy/rcgp-policy-areas/~media/Files/Policy/Assisted-Dying-Consultation/Assisted%20Dying%20Consultation%20Analysis.ashx> (Accessed 26 March 2015).
- 446 Royal College of Physicians (2014) "RCP reaffirms position against assisted dying". Press release, November 27 2014. Available at: <https://www.rcplondon.ac.uk/news/rcp-reaffirms-position-against-assisted-dying> (Accessed 9 December 2015).
- 447 Association for Palliative Medicine of Great Britain (2015) "Survey on Assisted Suicide 2015". Available at: <http://217.199.187.67/apmonline.org/wp-content/uploads/2015/05/APM-survey-on-Assisted-Suicide-website.pdf> (Accessed 9 December 2015).
- 448 Association for Palliative Medicine of Great Britain (2015) "Survey on Assisted Suicide 2015". Available at: <http://217.199.187.67/apmonline.org/wp-content/uploads/2015/05/APM-survey-on-Assisted-Suicide-website.pdf> (Accessed 9 December 2015).
- 449 House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill (2005) *Assisted Dying for the Terminally Ill Bill [HL] Vol I Report*. The Stationery Office: London. p.123.
- 450 Hagelin J, Nilstun T, Hau J *et al*. "Surveys on attitudes towards legalisation of euthanasia: importance of question phrasing." *J Med Ethics* 2004; **30**: 521-523.
- 451 Parkinson L, Rainbird K, Kerridge I *et al*. "Cancer patients' attitudes towards euthanasia and physician-assisted suicide: the influence of question wording and patients' own definitions on responses." *Journal of Bioethical Inquiry* 2005; **2**(2): 82-89.
- 452 Cox K, Bird L, Arthur A *et al*. "Public attitudes to death and dying in the UK: a review of published literature." *BMJ Supportive & Palliative Care* 2013; **3**: 37-45.
- 453 Donninson D, Bryson C "Matters of life and death: attitudes to euthanasia", in Jowell R, Curtice J, Park A *et al*. (eds.) (1996) *British Social Attitudes: the 13<sup>th</sup> Report*. Dartmouth: Aldershot.
- 454 Cley E, McLean S, Phillips M "Quickening death: the euthanasia debate", in Park A, Curtice J, Thompson K *et al*. (eds.) (2007) *British Social Attitudes: the 23<sup>rd</sup> Report – Perspectives on a changing society*. Sage: London.
- 455 Cley E, McLean S, Phillips M "Quickening death: the euthanasia debate", in Park A, Curtice J, Thompson K *et al*. (eds.) (2007) *British Social Attitudes: the 23<sup>rd</sup> Report – Perspectives on a changing society*. Sage: London. p.41.
- 456 Cley E, McLean S, Phillips M "Quickening death: the euthanasia debate", in Park A, Curtice J, Thompson K *et al*. (eds.) (2007) *British Social Attitudes: the 23<sup>rd</sup> Report – Perspectives on a changing society*. Sage: London. p.47.
- 457 McAndrew S "Religious faith and contemporary attitudes", in Park A, Curtice J, Thomson K *et al*. (eds.) (2010) *British Social Attitudes: 2009-2010. The 26<sup>th</sup> Report*. Sage: London. pp.87-113.

- 458 McAndrew S “Religious faith and contemporary attitudes”, in Park A, Curtice J, Thomson K *et al.* (eds.) (2010) *British Social Attitudes: 2009-2010. The 26th Report*. Sage: London. pp.87-113.
- 459 Gill R (1998) *Euthanasia and the Churches*. Cassell: London. p.21.
- 460 Gill R (2013) *Society Shaped by Theology*. Ashgate: Farnham. p.163.
- 461 Ipsos Mori (2015) “Economist Assisted dying research 2015”. Available at: <https://www.ipsos-mori.com/Assets/Docs/Polls/economist-assisted-dying-tables-jun-2015.pdf> (Accessed 14 August 2015).
- 462 YouGov (2014) “YouGov/Sunday Times survey results - Fieldwork: 3rd - 4th July 2014”. Available at: [http://d25d2506sfb94s.cloudfront.net/cumulus\\_uploads/document/ie4aa31iy7/YG-Archive-Pol-Sunday-Times-results-140704.pdf](http://d25d2506sfb94s.cloudfront.net/cumulus_uploads/document/ie4aa31iy7/YG-Archive-Pol-Sunday-Times-results-140704.pdf) (Accessed 11 March 2015).
- 463 YouGov (2012) “YouGov/Sunday Times survey results – Fieldwork: 28th - 29th June 2012”. Available at: [http://d25d2506sfb94s.cloudfront.net/cumulus\\_uploads/document/rpu120r18w/YG-Archives-Pol-ST-results-2906-010712.pdf](http://d25d2506sfb94s.cloudfront.net/cumulus_uploads/document/rpu120r18w/YG-Archives-Pol-ST-results-2906-010712.pdf) (Accessed 11 March 2013).
- 464 ComRes (2010) “BBC Panorama Poll on Assisted Suicide”. Available at: [http://comres.co.uk/wp-content/themes/comres/poll/BBC\\_Panorama\\_Results\\_31\\_Jan\\_2010.pdf](http://comres.co.uk/wp-content/themes/comres/poll/BBC_Panorama_Results_31_Jan_2010.pdf) (Accessed 11 March 2015).
- 465 ComRes (2011) “BBC Newsnight Assisted Suicide Poll”. Available at: [http://comres.co.uk/wp-content/themes/comres/poll/BBC\\_Newsnight\\_Assisted\\_Suicide\\_June11.pdf](http://comres.co.uk/wp-content/themes/comres/poll/BBC_Newsnight_Assisted_Suicide_June11.pdf) (Accessed 11 March 2015).
- 466 YouGov (2013) “YouGov / University of Lancaster Survey Results - Fieldwork: 25th – 30th January 2013”. Available at: [http://d25d2506sfb94s.cloudfront.net/cumulus\\_uploads/document/qsaxtu2j4/YG-Archive-University-of-Lancaster-300113-faith-matters-euthanasia.pdf](http://d25d2506sfb94s.cloudfront.net/cumulus_uploads/document/qsaxtu2j4/YG-Archive-University-of-Lancaster-300113-faith-matters-euthanasia.pdf) (Accessed 11 March 2015).
- 467 Populus (2015) “Dignity in Dying Poll – Fieldwork 11th – 19th March 2015”. Available at: <http://www.populus.co.uk/wp-content/uploads/DIGNITY-IN-DYING-Populus-poll-March-2015-data-tables-with-full-party-crossbreaks.compressed.pdf> (Accessed 19 August 2015).
- 468 Populus (2015) “Dignity in Dying Poll – Fieldwork 11th – 19th March 2015.” Available at: <http://www.populus.co.uk/wp-content/uploads/DIGNITY-IN-DYING-Populus-poll-March-2015-data-tables-with-full-party-crossbreaks.compressed.pdf> (Accessed 19 August 2015).
- 469 YouGov (2014) “YouGov / Dignity in Dying Survey Results Fieldwork: 19th – 20th October 2014”. Available at: [http://d25d2506sfb94s.cloudfront.net/cumulus\\_uploads/document/vyieu8z2jl/DignityinDyingResults\\_141020\\_assisted\\_dying\\_Website.pdf](http://d25d2506sfb94s.cloudfront.net/cumulus_uploads/document/vyieu8z2jl/DignityinDyingResults_141020_assisted_dying_Website.pdf) (Accessed 11 March 2015).
- 470 ComRes (2014) “CARE – Assisted Suicide Poll – Fieldwork 11th – 13th July 2014”. Available at: [http://comres.co.uk/wp-content/themes/comres/poll/Care\\_Assisted\\_Suicide\\_Poll\\_July\\_2014\\_\(with\\_summary\\_table\).pdf](http://comres.co.uk/wp-content/themes/comres/poll/Care_Assisted_Suicide_Poll_July_2014_(with_summary_table).pdf) (Accessed 19 August 2015).
- 471 Christian Action Research and Education. “Charity releases polling showing diminishing support for assisted suicide in practice”. *CARE Press Release*, 18 July 2014. Available at: <http://www.care.org.uk/news/latest-news/charity-releases-polling-showing-diminishing-support-assisted-suicide-practice> (Accessed 4 November 2015).
- 472 ComRes (2014) “Care not Killing/Not Dead Yet Health and Assisted Dying Poll – Fieldwork 31st October – 2nd November 2014”. Available at: [http://comres.co.uk/wp-content/uploads/2015/04/Not\\_Dead\\_Yet\\_CNK\\_Poll\\_November\\_2014.pdf](http://comres.co.uk/wp-content/uploads/2015/04/Not_Dead_Yet_CNK_Poll_November_2014.pdf) (Accessed 19 August 2015).
- 473 ComRes (2012) “CARE assisted suicide study – fieldwork 16th-18th December 2011”. Available at: [http://comres.co.uk/wp-content/themes/comres/poll/CARE\\_assisted\\_suicide\\_results\\_Jan\\_2012.pdf](http://comres.co.uk/wp-content/themes/comres/poll/CARE_assisted_suicide_results_Jan_2012.pdf) (Accessed 19 August 2015).
- 474 My Life, My Death, My Choice (2015) “More than three-quarters of Scots say “important” Assisted Suicide Bill becomes law”. Available at: <http://www.lifedeathchoice.org.uk/news/news/more-than-three-quarters-of-scots-say-important-assisted-suicide-bill-becomes-law/> (Accessed 11 March 2015).



- 475 "Majority of Scots in favour of assisted suicide, according to poll". *Herald Scotland*, May 24 2015. Available at: [http://www.heraldscotland.com/news/13215114.Majority\\_of\\_Scots\\_in\\_favour\\_of\\_assisted\\_suicide\\_\\_according\\_to\\_poll/](http://www.heraldscotland.com/news/13215114.Majority_of_Scots_in_favour_of_assisted_suicide__according_to_poll/) (Accessed 2 September 2015).
- 476 YouGov (2013) "YouGov/Dignity in Dying Survey results - Fieldwork: 11th - 13th November 2013". Available at: [http://d25d2506sfb94s.cloudfront.net/cumulus\\_uploads/document/tp47zuzfwiz/YG-Archive-131119-Dignity-in-dying.pdf](http://d25d2506sfb94s.cloudfront.net/cumulus_uploads/document/tp47zuzfwiz/YG-Archive-131119-Dignity-in-dying.pdf) (Accessed 11 March 2015).
- 477 ComRes (2012) "ALERT Assisted Suicide Poll - A public telephone poll on behalf of ALERT published 15/03/12". Available at: <http://comres.co.uk/polls/alert-assisted-suicide-poll/> (Accessed 11 March 2015).
- 478 ComRes (2011) "Scope Assisted Suicide Survey". Available at: [http://comres.co.uk/wp-content/themes/comres/poll/DPP\\_Assisted\\_suicide\\_tables\\_March\\_2011.pdf](http://comres.co.uk/wp-content/themes/comres/poll/DPP_Assisted_suicide_tables_March_2011.pdf) (Accessed 11 March 2015).
- 479 Scope (2014) "New research: Majority of disabled people fear change to assisted suicide law". Press release, July 17 2014. Available at: <http://www.scope.org.uk/media/press-releases/july-2014/assisted-suicide-law> (Accessed 10 March 2015).
- 480 Ipsos Mori (2012) "Religious and Social Attitudes of UK Christians in 2011". Available at: <https://www.ipsos-mori.com/researchpublications/researcharchive/2921/Religious-and-Social-Attitudes-of-UK-Christians-in-2011.aspx> (Accessed 26 March 2015).
- 481 YouGov (2013) "YouGov/Dignity in Dying Fieldwork: 22nd - 24th April 2013". Available at: [http://cdn.yougov.com/cumulus\\_uploads/document/qfxmkoee6/YG-Archive-Dignity-in-Dying-results-240413-assisted-dying-full-religion.pdf](http://cdn.yougov.com/cumulus_uploads/document/qfxmkoee6/YG-Archive-Dignity-in-Dying-results-240413-assisted-dying-full-religion.pdf) (Accessed 12 November 2015).
- 482 YouGov (2013) "YouGov/University of Lancaster Survey Results – Fieldwork: 25th – 30th January 2013". Available at: [http://d25d2506sfb94s.cloudfront.net/cumulus\\_uploads/document/qsaxtu2j4/YG-Archive-University-of-Lancaster-300113-faith-matters-euthanasia.pdf](http://d25d2506sfb94s.cloudfront.net/cumulus_uploads/document/qsaxtu2j4/YG-Archive-University-of-Lancaster-300113-faith-matters-euthanasia.pdf) (Accessed 12 November 2015).
- 483 Williams N, Dunford C, Knowles A *et al.* "Public attitudes to life sustaining treatments and euthanasia in dementia". *International Journal of Geriatric Psychiatry* 2007; **22**: 1229-1234.
- 484 Williams N, Dunford C, Knowles A *et al.* "Public attitudes to life sustaining treatments and euthanasia in dementia". *International Journal of Geriatric Psychiatry* 2007; **22**: 1232.
- 485 Chapple A, Zieblands S, McPherson A *et al.* "What people close to death say about euthanasia and assisted suicide: a qualitative study". *J Med Ethics* 2006; **32**: 706-710.
- 486 Hendry M, Pasterfield D, Lewis R *et al.* "Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying". *Palliat Med* 2012; **27**(1): 13-26.
- 487 Lewis P, Black I (2012) *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Commissioned by the Commission on Assisted Dying. Available at: <http://www.commissiononassisteddying.co.uk/wp-content/uploads/2012/01/Penney-Lewis-briefing-paper.pdf> (Accessed 20 November 2015).
- 488 Lovett I, Pérez-Peña R "California Governor Signs Assisted Suicide Bill into Law". *The New York Times*, Monday 5 October 2015. Available at: [http://www.nytimes.com/2015/10/06/us/california-governor-signs-assisted-suicide-bill-into-law.html?\\_r=0](http://www.nytimes.com/2015/10/06/us/california-governor-signs-assisted-suicide-bill-into-law.html?_r=0) (Accessed 20 November 2015).
- 489 The full text of the Act can be found online at: [http://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill\\_id=201520162AB15](http://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201520162AB15) (Accessed 20 November 2015).
- 490 Bernstein S "California governor signs bill legalizing physician-assisted suicide". *Reuters*, Monday 5 October 2015. Available at: <http://uk.reuters.com/article/2015/10/05/us-usa-california-assisted-suicide-idUKKCN0RZ2BI20151005> (Accessed 20 November 2015).
- 491 Hoffman M. *Petition on AB X 2-15*. Available at: [https://www.oag.ca.gov/system/files/initiatives/pdfs/15-0080%20\(Referendum%20of%20ABX2-15\)\\_0.pdf](https://www.oag.ca.gov/system/files/initiatives/pdfs/15-0080%20(Referendum%20of%20ABX2-15)_0.pdf) (Accessed 20 November 2015).
- 492 *Carter v Canada (Attorney General)* [2015] SCC 5.

- 493 Kirkey S "Federal government appoints panel to review assisted dying, but critics fear bias". *National Post*, 17 July 2015. Available at: <http://news.nationalpost.com/news/canada/federal-government-appoints-panel-to-review-assisted-dying-but-critics-fear-bias> (Accessed 20 November 2015).
- 494 *Baxter v Montana* 2009 MT 449.
- 495 *Morris (and others) v Brandenburg* (No D-202-CV 2012-02909): State of New Mexico, County of Bernalillo, Second Judicial District Court: Nan G Nash, District Court Judge.
- 496 Reichbach M "Court of Appeals reverses district court decision on aid in dying". *New Mexico Political Report*, 12 August 2015. Available at: <http://nmpoliticalreport.com/9651/no-aid-in-dying-right-in-nm-says-appeals-court-supreme-court-next/> (Accessed 20 November 2015).
- 497 Nicol J, Tiedemann M, Valiquet D (2011, revised 2013) *Euthanasia and Assisted Suicide: International Experiences*. Publication No. 2011-67-E. Canadian Library of Parliament, Legal and Social Affairs Division: Ottawa. p. 19.
- 498 Cook M "Colombia may finally legalise euthanasia". *Bioedge*, 21 February 2015. Available at: [http://www.bioedge.org/index.php/bioethics/bioethics\\_article/11339](http://www.bioedge.org/index.php/bioethics/bioethics_article/11339) (Accessed 20 November 2015).
- 499 Cook M "Colombia close to legal euthanasia". *Bioedge*, 25 April 2015. Available at: <http://www.bioedge.org/bioethics/colombia-close-to-legal-euthanasia/11411> (Accessed 20 November 2015).
- 500 Martin S "Colombian Physicians Get the Final Go-Ahead for Euthanasia". *Pan Am Post*, 23 April 2015. Available at: <http://panampost.com/sabrina-martin/2015/04/23/colombian-physicians-get-the-final-go-ahead-for-euthanasia/> (Accessed 20 November 2015).
- 501 Fleming JI "Death, Dying, and Euthanasia: Australia versus the Northern Territory". *Issues Law Med* (2000); **15**(3): 291-295.
- 502 Richmond DE "A critical analysis of the End of Life Choice Bill 2013". *NZ Med J* 2014; **127**(1397): 77-87.
- 503 Savage J "Lecretia Seales's husband: 'Her reaction utterly broke my heart'". *New Zealand Herald*, Friday 5 June 2015. Available at: [http://www.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=11460486](http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11460486) (Accessed 20 November 2015).
- 504 Jones N "Parliament to hold euthanasia inquiry". *New Zealand Herald*, Wednesday 22 July 2015. Available at: [http://m.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=11485132](http://m.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11485132) (Accessed 20 November 2015).
- 505 "Tasmania's euthanasia bill fails narrowly". *news.co.au*. Available at: <http://www.news.com.au/national/breaking-news/tasmanias-euthanasia-bill-fails-narrowly/story-e6frfku9-1226741999723> (Accessed 20 November 2015).
- 506 *Fleming v Ireland (and others)* [2013] IESC 19.
- 507 Reiss M "Connecticut Considers Assisted Suicide Bill". *NBC Connecticut*, 18 March 2015. Available at: <http://www.nbcconnecticut.com/news/local/Connecticut-Considers-Assisted-Suicide-Bill-296805751.html> (Accessed 20 November 2015).
- 508 Lovett K "Timothy Cardinal Dolan will fight efforts in New York to legalise physician-assisted-suicide". *New York Daily News*, Monday 9 February 2015. Available at: <http://www.nydailynews.com/new-york/timothy-cardinal-dolan-fight-bill-assisted-suicide-article-1.2107898> (Accessed 20 November 2015).
- 509 Chokshi N "Christie may face a decision on assisted suicide in New Jersey". *The Washington Post*, 19 November 2014. Available at: <http://www.washingtonpost.com/blogs/govbeat/wp/2014/11/19/christie-may-face-a-decision-on-assisted-suicide-in-new-jersey/> (Accessed 20 November 2015).
- 510 Deutsche Welle "German parliament introduces bills on assisted suicide". *Deutsche Welle*, 9 June 2015. Available at: <http://www.dw.com/en/german-parliament-introduces-bills-on-assisted-suicide/a-18505698> (Accessed 20 November 2015).
- 511 "South African Court grants man 'right to die.'" *BBC News Online*, 30 April 2015. Available at: <http://www.bbc.co.uk/news/world-africa-32530580> (Accessed 20 November 2015).

- 512 Rietjens JA, van der Maas PJ, Onwuteaka-Philipsen BD *et al.* "Two Decades of  
Research on Euthanasia from the Netherlands: What Have We Learnt and What  
Questions Remain?" *J Bioeth Inq* 2009; **6**(3): 271-83.
- 513 Griffiths J, Bood A, Weyers H (1998) *Euthanasia and Law in the Netherlands*.  
Amsterdam University Press: Amsterdam. p.63.
- 514 Rietjens JA, van der Maas PJ, Onwuteaka-Philipsen BD *et al.* "Two Decades of  
Research on Euthanasia from the Netherlands: What Have We Learnt and What  
Questions Remain?" *J Bioeth Inq* 2009; **6**(3): 271-83.
- 515 Sheldon T "The doctor who prescribed suicide: Was the Dutch psychiatrist Dr  
Boudewijn Chabot right to help a sane, healthy woman to take her own life?"  
*The Independent*, 30 June 1994. Available at [https://www.independent.co.uk/  
life-style/the-doctor-who-prescribed-suicide-was-the-dutch-psychiatrist-dr-  
boudewijn-chabot-right-to-help-a-sane-healthy-woman-to-take-her-own-life-  
tony-sheldon-reports-1425973.html](https://www.independent.co.uk/life-style/the-doctor-who-prescribed-suicide-was-the-dutch-psychiatrist-dr-boudewijn-chabot-right-to-help-a-sane-healthy-woman-to-take-her-own-life-tony-sheldon-reports-1425973.html) (Accessed 20 November 2015).
- 516 Sheldon T "Being 'tired of life' is not grounds for euthanasia." *BMJ* 2003; **326**: 71.
- 517 Verhagen E, Sauer PJJ "The Groningen Protocol – Euthanasia in Severely Ill  
Newborns". *N Eng J Med* 2005; **352**: 959-62.
- 518 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in  
English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%20  
2013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 519 Regional Euthanasia Review Committees (2003) *Annual Report 2002*. Available (in  
English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20Report%20  
2002\\_40762.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20Report%202002_40762.pdf) (Accessed 20 November 2015).
- 520 Statistics Netherlands (2014) *Mortality: Key Figures*. Available at [http://statline.  
cbs.nl/StatWeb/publication/?VW=T&DM=SLEN&PA=37979eng&LA=EN](http://statline.cbs.nl/StatWeb/publication/?VW=T&DM=SLEN&PA=37979eng&LA=EN)  
(Accessed 20 November 2015).
- 521 Kimsma GK "Death by request in the Netherlands: facts, the legal context, and  
effects on physicians, patients and families". *Med Health Care and Philos* 2010; **13**:  
355-61.
- 522 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in  
English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%20  
2013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 523 Groenewoud JH, van der Heide A, Onwuteaka-Philipsen BD *et al.* "Clinical  
problems with the performance of euthanasia and physician-assisted suicide in  
the Netherlands." *New Eng J Med* 2000; **342**(8): 551-6.
- 524 Grosse C, Grosse A "Assisted suicide: Models of legal regulation in selected  
European countries and the case law of the European Court of Human Rights."  
*Med Sci Law* 2014; **0**(0): 1-13.
- 525 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in  
English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%20  
2013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 526 Grosse C, Grosse A "Assisted suicide: Models of legal regulation in selected  
European countries and the case law of the European Court of Human Rights".  
*Med Sci Law* 2014; **0**(0): 1-13.
- 527 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in  
English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%20  
2013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 528 Bolt EE, Snijdewind MC, Willems DL *et al.* "Can physicians conceive of performing  
euthanasia in cases of psychiatric disease, dementia or being tired of living?" *J  
Med Ethics* 2015; **0**: 1-7.
- 529 Rietjens JAC, van Tol DG, Schermer M *et al.* "Judgement of suffering in the case of a  
euthanasia request in the Netherlands". *J Med Ethics* 2009; **35**: 502-507.
- 530 Snijdewind MC, Willems DL, Deliëns L *et al.* "A Study of the First Year of the End  
of Life Clinic for Physician-Assisted Dying in the Netherlands". *JAMA Intern Med*  
2015; Aug 10. doi: 10.1001/jamainternmed.2015.3978.
- 531 Bolt EE, Snijdewind MC, Willems DL *et al.* "Can physicians conceive of performing  
euthanasia in cases of psychiatric disease, dementia or being tired of living?" *J  
Med Ethics* 2015; **0**: 1-7.

- 532 Sheldon T "Being 'tired of life' is not grounds for euthanasia". *BMJ* 2003; **326**: 71.
- 533 Bolt EE, Snijdewind MC, Willems DL *et al*. "Can physicians conceive of performing euthanasia in cases of psychiatric disease, dementia or being tired of living?" *J Med Ethics* 2015; **0**: 1-7.
- 534 Legemaate J, Bolt I "The Dutch Euthanasia Act: recent legal developments". *Eur J Health Law* 2013; **20**: 451-69.
- 535 Rurup ML, Muller MT, Onwuteaka-Philipsen BD *et al*. "Requests for euthanasia or physician-assisted suicide from older persons who do not have a severe disease: an interview study". *Psychol Med* 2005; **35**(5): 665-71.
- 536 Rurup ML, Muller MT, Onwuteaka-Philipsen BD *et al*. "Requests for euthanasia or physician-assisted suicide from older persons who do not have a severe disease: an interview study". *Psychol Med* 2005; **35**(5): 665-71.
- 537 Bolt EE, Snijdewind MC, Willems DL *et al*. "Can physicians conceive of performing euthanasia in cases of psychiatric disease, dementia or being tired of living?" *J Med Ethics* 2015; **0**: 1-7.
- 538 Raijmakers NJH, van der Heide A, Kouwenhoven PSC *et al*. "Assistance in dying for older people without a serious medical condition who have a wish to die: a national cross-sectional survey". *J Med Ethics* 2015; **41**: 145-50.
- 539 Rurup ML, Smets T, Cohen J *et al*. "The First Five Years of Euthanasia Legislation in Belgium and the Netherlands: Description and Comparison of Cases". *Palliat Med* 2012; **26**(1): 43-9.
- 540 As reported in Lewis P, Black I "Adherence to the Request Criterion in Jurisdictions Where Assisted Dying is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon and Switzerland". *J Law Med Ethics* 2013; **41**(4): 885-898.
- 541 As referred to in *Carter v Canada (Attorney General)* [2012] BCSC 886, at 483.
- 542 Rietjens JAC, van der Maas PJ, Onwuteaka-Philipsen BD *et al*. "Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?" *Bioethical Inquiry* 2009; **6**: 271-83.
- 543 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 544 Buiting H, van Delden J, Onwuteaka-Philipsen B *et al*. "Reporting of euthanasia and physician-assisted suicide in the Netherlands: descriptive study". *BMC Medical Ethics* 2009; **10**: 18.
- 545 Quoted in: Lewis P, Black I "Adherence to the Request Criterion in Jurisdictions Where Assisted Dying is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon and Switzerland". *J Law Med Ethics* 2013; **41**(4): 885-898.
- 546 Quoted in: Lewis P, Black I "Adherence to the Request Criterion in Jurisdictions Where Assisted Dying is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon and Switzerland". *J Law Med Ethics* 2013; **41**(4): 885-898.
- 547 Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G "Granted, Undecided, Withdrawn, and Refused Requests for Euthanasia and Physician-Assisted Suicide." *Arch Intern Med* 2005; **165**: 1698-704.
- 548 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 549 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 550 Groenewoud JH, Van Der Heide A, Tholen AJ *et al*. "Psychiatric consultation with regard to requests for euthanasia or physician-assisted suicide". *Gen Hosp Psychiatry* 2004; **26**(4): 323-30.
- 551 Levene I, Parker M "Prevalence of Depression in Granted and Refused Requests for Euthanasia and Assisted Suicide: A Systematic Review". *J Med Ethics* 2011; **37**(4): 205-11.

- 552 Onwuteaka-Philipsen BD, Rurup ML, Pasman HR *et al.* "The last phase of life: who requests and who receives euthanasia or physician-assisted suicide?" *Med Care* 2010; **48**(7): 596-603.
- 553 Quoted in: Lewis P, Black I (2012) *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Available at: <http://www.commissiononassisteddying.co.uk/wp-content/uploads/2012/01/Penney-Lewis-briefing-paper.pdf> (Accessed 9 December 2015).
- 554 Lewis P, Black I (2012) *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Available at: <http://www.commissiononassisteddying.co.uk/wp-content/uploads/2012/01/Penney-Lewis-briefing-paper.pdf> (Accessed 9 December 2015).
- 555 As reported in: Lewis P, Black I "Adherence to the Request Criterion in Jurisdictions Where Assisted Dying is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon and Switzerland". *J Law Med Ethics* 2013; **41**(4): 885-898.
- 556 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 557 Groenewoud JH, van der Heide A, Onwuteaka-Philipsen BD *et al.* "Clinical Problems with the performance of euthanasia and physician-assisted suicide in the Netherlands". *New Eng J Med* 2000; **342**(8): 551-6.
- 558 van der Maas PJ, Pijnenborg L, van Delden JJM "Changes in Dutch Opinions on Active Euthanasia, 1966 Through 1991". *JAMA* 1995; **273**(18): 1411-14.
- 559 Kimsma GK "Death by request in The Netherlands: facts, the legal context and effects on physicians, patients and families". *Med Health Care and Philos* 2010; **13**: 355-361.
- 560 Haverkate I, van der Heide A, Onwuteaka-Philipsen BD *et al.* "The emotional impact on physicians of hastening the death of a patient". *Med J Aust* 2001; **175**(10): 519-22.
- 561 Voorhees JR, Rietjens JAC, van der Heide A *et al.* "Discussing Physician-Assisted Dying: Physicians' Experiences in the United States and the Netherlands". *Gerontologist* 2014; **54**(5): 808-17.
- 562 Lewis P, Black I (2012) *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Available at: <http://www.commissiononassisteddying.co.uk/wp-content/uploads/2012/01/Penney-Lewis-briefing-paper.pdf> (Accessed 9 December 2015). p.34.
- 563 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 564 Regional Euthanasia Review Committees (2014) *Annual Report 2013*. Available (in English) at [https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013\\_41743.pdf](https://www.euthanasiecommissie.nl/doc/pdf/Annual%20report%202013_41743.pdf) (Accessed 20 November 2015).
- 565 Chambaere K, Centeno C, Hernandez EA *et al.* (2011) *Palliative Care Development in Countries with a Euthanasia Law: Report for the Commission on Assisted Dying Briefing Papers*. European Association for Palliative Care, Clinica Universidad de Navarra/Ghent University & Vrije Universiteit Brussels End of Life Care Research Group.
- 566 Chambaere K, Bernheim JL "Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience". *J Med Ethics* 2015; **41**: 657-60.
- 567 Chambaere K, Centeno C, Hernandez EA *et al.* (2011) *Palliative Care Development in Countries with a Euthanasia Law: Report for the Commission on Assisted Dying Briefing Papers*. European Association for Palliative Care, Clinica Universidad de Navarra/Ghent University & Vrije Universiteit Brussels End of Life Care Research Group.
- 568 Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G "Requests for euthanasia and physician-assisted suicide and the availability and application of palliative options" *Palliat Support Care* 2006; **4**(4): 399-406.

- 569 Onwuteaka-Philipsen BD, Rurup ML, Pasma HR *et al.* "The last phase of life: who requests and who receives euthanasia or physician-assisted suicide?" *Med Care* 2010; **48**(7): 596-603.
- 570 Traynor I "Belgian law on euthanasia for children, with no age limit, will be first in the world." *The Guardian*, Wednesday 12 February 2014. Available at <http://www.theguardian.com/world/2014/feb/12/belgium-legalise-euthanasia-children-age-limit> (Accessed 2 December 2015).
- 571 Thienpont L, Verhofstadt M, van Loon T *et al.* "Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study." *BMJ Open*, 2015; **5**: e:007454.
- 572 Federal Committee for the Monitoring and Assessment of Euthanasia (2014) *Sixth Report to the Legislative Chambers 2012-13*. Available (in French or Dutch) at: <http://www.health.fgov.be/eportal/Healthcare/Consultativebodies/Commissions/Euthanasia/Publications/index.htm#VmhabLiyOko> (Accessed 9 December 2015).
- 573 Federal Committee for the Monitoring and Assessment of Euthanasia (2014) *Sixth Report to the Legislative Chambers 2012-13*. Available (in French or Dutch) at: <http://www.health.fgov.be/eportal/Healthcare/Consultativebodies/Commissions/Euthanasia/Publications/index.htm#VmhabLiyOko> (Accessed 9 December 2015).
- 574 Waterfield B "Belgian killed by euthanasia after a botched sex change operation". *The Telegraph*, 1 October 2013. Available at: <http://www.telegraph.co.uk/news/worldnews/europe/belgium/10346616/Belgian-killed-by-euthanasia-after-a-botched-sex-change-operation.html> (Accessed 27 November 2015).
- 575 Hall J "Identical twins die after seeking euthanasia when they discovered they would go blind and never see each other again". *The Independent*, Monday 5 March 2013. Available at: <http://www.independent.co.uk/news/world/europe/identical-twins-die-after-seeking-euthanasia-when-they-discovered-they-would-go-blind-and-never-see-each-other-again-8451217.html> (Accessed 27 November 2015).
- 576 Waterfield B "Son challenges Belgian law after mother's mercy killing". *The Telegraph*, 2 February 2015. Available at: <http://www.telegraph.co.uk/news/worldnews/europe/belgium/11382843/Son-challenges-Belgian-law-after-mothers-mercy-killing.html> (Accessed 27 November 2015).
- 577 Thienpont L, Verhofstadt M, van Loon T *et al.* "Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study". *BMJ Open*, 2015; **5**: e:007454.
- 578 Van Wesemael Y, Cohen J, Bilsen J *et al.* "Process and outcomes of euthanasia requests under the Belgian Act on Euthanasia: a nationwide study". *J Pain Symptom Manage* 2011; **42**(5): 721-33.
- 579 Federal Committee for the Monitoring and Assessment of Euthanasia (2014) *Sixth Report to the Legislative Chambers 2012-13*. Available (in French or Dutch) at: <http://www.health.fgov.be/eportal/Healthcare/Consultativebodies/Commissions/Euthanasia/Publications/index.htm#VmhabLiyOko> (Accessed 9 December 2015).
- 580 Rurup ML, Smets T, Cohen J *et al.* "The First Five Years of Euthanasia Legislation in Belgium and the Netherlands: Description and Comparison of Cases". *Palliat Med* 2012; **26**(1): 43-9.
- 581 Chambaere K, Bernheim JL, Downar J *et al.* "Characteristics of Belgian 'life-ending acts without explicit patient request': a large scale death certificate survey revisited". *CMAJ Open* 2014; **2**(4): e262-e267.
- 582 Smets T, Bilsen J, Cohen J *et al.* "Reporting of euthanasia in medical practice in Flanders Belgium: cross-sectional analysis of reported and unreported cases". *BMJ* 2010; **341**: c5174.
- 583 Chambaere K, Vander Stichele R, Mortier F *et al.* "Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium". *New Eng J Med* 2015; **372**(12): 1179-80.

- 584 Federal Committee for the Monitoring and Assessment of Euthanasia (2014) *Sixth Report to the Legislative Chambers 2012-13*. Available (in French or Dutch) at: <http://www.health.fgov.be/eportal/Healthcare/Consultativebodies/Commissions/Euthanasia/Publications/index.htm#VmhabLiyOko> (Accessed 9 December 2015).
- 585 Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G "Granted, Undecided, Withdrawn and Refused Requests for Euthanasia and Physician-Assisted Suicide." *Arch Intern Med* 2005; **165**: 1698-1704.
- 586 Federal Committee for the Monitoring and Assessment of Euthanasia (2014) *Sixth Report to the Legislative Chambers 2012-13*. Available (in French or Dutch) at: <http://www.health.fgov.be/eportal/Healthcare/Consultativebodies/Commissions/Euthanasia/Publications/index.htm#VmhabLiyOko> (Accessed 9 December 2015).
- 587 Van Wesemael Y, Cohen J, Bilsen J *et al.* "Process and outcomes of euthanasia requests under the Belgian Act on Euthanasia: a nationwide survey". *J Pain Symptom Manage* 2011; **42**(5): 721-33.
- 588 Thienpont L, Verhofstadt M, van Loon T *et al.* "Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study. *BMJ Open*, 2015; **5**: e:007454.
- 589 Federal Committee for the Monitoring and Assessment of Euthanasia (2014) *Sixth Report to the Legislative Chambers 2012-13*. Available (in French or Dutch) at: <http://www.health.fgov.be/eportal/Healthcare/Consultativebodies/Commissions/Euthanasia/Publications/index.htm#VmhabLiyOko> (Accessed 9 December 2015).
- 590 Smets T, Cohen J, Bilsen J *et al.* "Attitudes and Experiences of Belgian Physicians Regarding Euthanasia Practice and the Euthanasia Law". *J Pain Symptom Manage* 2011; **41**(3): 580-93.
- 591 Belgian Act on Euthanasia s.3.2.3.
- 592 Bernheim J, Deschepper R, Distelmans W "Development of palliative care and legalisation of euthanasia: antagonism or synergy?" *BMJ* 2008; **336**: 864-867.
- 593 Dierickx S, Deliens L, Cohen J *et al.* "Comparison of the Expressing and Granting of Requests for Euthanasia in Belgium in 2007 vs 2013". *JAMA Intern Med* 2015; Aug 10. doi: 10.1001/jamainternmed.2015.3982.
- 594 Bilsen J, Vander Stichele R, Broeckaert B *et al.* "Changes in medical end-of-life practices during the legalization process of euthanasia in Belgium". *Soc Sci Med* 2007; **65**(4): 803-8.
- 595 Chambaere K, Vander Stichele R, Mortier F *et al.* "Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium". *New Eng J Med* 2015; **372**(12): 1179-80.
- 596 Chambaere K, Centeno C, Hernandez EA *et al.* (2011) *Palliative Care Development in Countries with a Euthanasia Law: Report for the Commission on Assisted Dying Briefing Papers*. European Association for Palliative Care, Clinica Universidad de Navarra/Ghent University & Vrije Universiteit Brussel End of Life Care Research Group.
- 597 Chambaere K, Bernheim JL "Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience. *J Med Ethics* 2015; **41**: 657-60.
- 598 Smets T, Cohen J, Bilsen J *et al.* "Attitudes and Experiences of Belgian Physicians Regarding Euthanasia Practice and the Euthanasia Law". *J Pain Symptom Manage* 2011; **41**(3): 580-93.
- 599 Oregon Public Health Division (2015) *Oregon resident deaths by month of death and county of residence, 2014 final data*. Available at: <https://public.health.oregon.gov/BirthDeathCertificates/VitalStatistics/death/Pages/index.aspx> (Accessed 27 November 2015).
- 600 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 601 Ganzini L "Lessons from Legalized Physician-Assisted Death in Oregon and Washington" in Quill TE, Miller FG (eds.) (2014) *Palliative Care and Ethics*. Oxford University Press: Oxford. pp. 266-280.

- 602 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 603 Tolle SW, Tilden VR, Drach LL *et al*. "Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide". *J Clin Ethics* 2014; **15**(2): 111-18.
- 604 Jones DA, Paton D "How does legalization of physician-assisted suicide affect rates of suicide?" *Southern Medical Journal* 2015; **108**(10): 599-604.
- 605 Oregon Health Authority: Public Health Division (2015) *FAQs about the Death with Dignity Act*. Available at <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/faqs.pdf> (Accessed 27 November 2015).
- 606 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 607 Death with Dignity Act 1994, s.3.01(g)
- 608 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 609 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 610 Please see the annual reports on the operation of the Death with Dignity Act from the Oregon Public Health Division for the years 2005, 2010, 2011 and 2012. Available at: <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx> (Accessed 9 December 2015).
- 611 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 612 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 613 Ganzini L, Nelson HD, Lee MA *et al*. "Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act". *JAMA* 2001; **285**(18): 2363-9.
- 614 Lee MA, Nelson HD, Tilden VP. "Legalizing assisted suicide – views of physicians in Oregon". *New Eng J Med* 1996; **334**(5): 310-15.
- 615 Reported in: Lewis P, Black I "Adherence to the Request Criterion in Jurisdictions Where Assisted Dying is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon and Switzerland". *J Law Med Ethics* 2013; **41**(4): 885-898.
- 616 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 617 Ganzini L "Lessons from Legalized Physician-Assisted Death in Oregon and Washington" in Quill TE, Miller FG (eds.) (2014) *Palliative Care and Ethics*. Oxford University Press: Oxford.
- 618 Ganzini L, Nelson HD, Schmidt TA *et al*. "Physicians' experiences with the Oregon Death with Dignity Act." *New Eng J Med* 2000; **342**: 557-63.
- 619 Smith KA, Harvath TA, Goy ER *et al*. "Predictors of Pursuit of a Physician-Assisted Death". *J Pain Sym Manage* 2015; **49**(3): 555-561.
- 620 Ganzini L, Goy ER, Dobscha SK. "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross-sectional survey". *BMJ* 2008; **337**: a1682.
- 621 McCormack R, Fléchaïs R "The Role of Psychiatrists and Mental Disorder in Assisted Dying Practices Around the World: A Review of Legislation and Official Reports". *Psychosomatics* 2012; **53**: 319-26.
- 622 Death with Dignity Act 1994, s. 3.03.
- 623 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 624 Kissane DW, Street A, Nitschke P "Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia". *Lancet* 1998; **352**: 1097-1102.
- 625 Lee MA, Nelson HD, Tilden VP *et al*. "Legalizing assisted suicide – views of physicians in Oregon". *New Eng J Med* 1996; **334**: 310-15.



- 626 Ganzini L, Nelson HD, Lee MA *et al.* "Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act". *JAMA* 2001; **285**(18): 2363-9.
- 627 Ganzini L, Fenn DS, Lee MA *et al.* "Attitudes of Oregon psychiatrists to physician-assisted suicide". *Am J Psychiatry* 1996; **153**: 1469-75.
- 628 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 629 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 630 Battin MP, van der Heide A, Ganzini L *et al.* "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups". *J Med Ethics* 2007; **33**: 591-597.
- 631 Finlay IG, George R "Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact of patients in vulnerable groups – another perspective on Oregon's data". *J Med Ethics* 2011; **37**: 171-174.
- 632 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 633 Commission on Assisted Dying (2012) '*The current status of assisted dying is inadequate and incoherent...*' Available at: [http://www.demos.co.uk/files/476\\_CoAD\\_FinalReport\\_158x240\\_I\\_web\\_single-NEW\\_.pdf?1328113363](http://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_I_web_single-NEW_.pdf?1328113363) (Accessed 27 November 2015). p.254.
- 634 Ganzini L, Nelson HD, Lee MA *et al.* "Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act". *JAMA* 2001; **285**(18): 2363-9.
- 635 Oregon Public Health Division (1999) *Oregon's Death with Dignity Act: The First Year's Experience*. Department of Health: Oregon.
- 636 Dobscha SK, Heintz RT, Press N *et al.* "Oregon physicians' responses to requests for assisted suicide: a qualitative study". *J Palliat Med* 2004; **7**(3): 451-61.
- 637 Ganzini L, Nelson HD, Lee MA *et al.* "Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act". *JAMA* 2001; **285**(18): 2363-9.
- 638 Lee MA, Nelson HD, Tilden VP *et al.* "Legalizing assisted suicide – views of physicians in Oregon." *New Eng J Med* 1996; **344**: 310-315.
- 639 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 640 Voorhees JR, Rietjens JAC, van der Heide A *et al.* "Discussing Physician-Assisted Dying: Physicians' Experiences in the United States and the Netherlands". *Gerontologist* 2014; **54**(5): 808-17.
- 641 Ganzini L, Nelson HD, Lee MA *et al.* "Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act". *JAMA* 2001; **285**(18): 2363-9.
- 642 Back AL, Starks H, Hsu C *et al.* "Clinician-Patient Interactions About Requests for Physician-Assisted Suicide: A Patient and Family View". *Arch Intern Med* 2002; **162**(11): 1257-65.
- 643 Voorhees JR, Rietjens JAC, van der Heide A *et al.* "Discussing Physician-Assisted Dying: Physicians' Experiences in the United States and the Netherlands". *Gerontologist* 2014; **54**(5): 808-17.
- 644 Ganzini L, Nelson HD, Lee MA *et al.* "Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act". *JAMA* 2001; **285**(18): 2363-9.
- 645 Voorhees JR, Rietjens JAC, van der Heide A *et al.* "Discussing Physician-Assisted Dying: Physicians' Experiences in the United States and the Netherlands". *Gerontologist* 2014; **54**(5): 808-17.
- 646 Ganzini L "Lessons from Legalized Physician-Assisted Death in Oregon and Washington" in Quill TE, Miller FG (eds.) (2014) *Palliative Care and Ethics*. Oxford University Press: Oxford. pp. 266-280.
- 647 Ganzini L "Lessons from Legalized Physician-Assisted Death in Oregon and Washington" in Quill TE, Miller FG (eds.) (2014) *Palliative Care and Ethics*. Oxford University Press: Oxford. pp.266-280. p.270.

- 648 House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill (2005) *Assisted Dying for the Terminally Ill Bill: Volume II: Evidence*. The Stationery Office: London. p.257.
- 649 Ganzini L, Nelson HD, Lee MA *et al*. "Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act." *JAMA* 2001; **285**(18): 2363-9.
- 650 Ganzini L, Nelson HD, Lee MA *et al*. "Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Oregon Death with Dignity Act". *JAMA* 2001; **285**(18): 2363-9.
- 651 Ganzini L, Nelson HD, Schmidt TA *et al*. "Physicians' experiences with the Oregon Death with Dignity Act". *N Eng J Med* 2000; **342**(8): 557-563.
- 652 Oregon Public Health Division (2015) *Oregon's Death with Dignity Act: Annual Report 2014*. Department of Health: Oregon.
- 653 Lindsay RA "Oregon's experience: evaluating the record." *Am J Bioethics* 2009; **9**(3): 19-27.
- 654 Lindsay RA "Oregon's experience: evaluating the record." *Am J Bioethics* 2009; **9**(3): 19-27. p.22.
- 655 Swiss Academy of Medical Sciences (2004, updated 2013) *Medical Ethical Guidelines: End-of-Life Care*. SAMS: Basel.
- 656 Swiss Confederation (2012) *Cause of Death Statistics 2009: Assisted suicide and suicide in Switzerland*. Federal Statistical Office (FSO): Neuchâtel.
- 657 Bosshard G, Ulrich E and Bär W 748 cases of suicide assisted by a Swiss right-to-die organisation. *Swiss Med Wkly* 2003; **133**: 310-7.
- 658 Ogden RD, Hamilton WK, Whitcher C "Assisted suicide by oxygen deprivation with helium at a Swiss right-to-die organisation". *J Med Ethics* 2009; **36**: 174-9.
- 659 Lewis P, Black I (2012) *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Commissioned by the Commission on Assisted Dying. Available at <http://www.commissiononassisteddying.co.uk/wp-content/uploads/2012/01/Penney-Lewis-briefing-paper.pdf> (Accessed 20 November 2015).
- 660 Bosshard G, Ulrich E and Bär W 748 cases of suicide assisted by a Swiss right-to-die organisation. *Swiss Med Wkly* 2003; **133**: 310-17.
- 661 Swiss Academy of Medical Sciences (2004, updated 2013) *Medical Ethical Guidelines: End-of-Life Care*. SAMS: Basel.
- 662 Swiss Confederation (2012) *Cause of Death Statistics 2009: Assisted suicide and suicide in Switzerland*. Federal Statistical Office (FSO): Neuchâtel.
- 663 Black I "Suicide assistance for mentally disordered individuals in Switzerland and the state's positive obligation to facilitate dignified suicide." *Med Law Rev* 2012; **20**(1): 157-66.
- 664 Black I "Suicide assistance for mentally disordered individuals in Switzerland and the state's positive obligation to facilitate dignified suicide." *Med Law Rev* 2012; **20**(1): 157-66.
- 665 *Gross v Switzerland* [2013] ECHR 429, at 69.
- 666 Pasman HRW, Rurup ML, Willems DL *et al*. "Concept of unbearable suffering in context of ungranted requests for euthanasia. Qualitative interviews with patients and physicians". *BMJ* 2009; **339**: b4362.
- 667 Fischer S, Huber CA, Furter M *et al*. "Reasons why people in Switzerland seek assisted suicide: the view of patients and physicians". *Swiss Med Weekly* 2009; **139** (23-24): 333-338.
- 668 Kohlwes RJ, Koepsell TD, Rhodes LA *et al*. "Physicians' responses to patients' requests for physician-assisted suicide". *Arch Intern Med* 2001; **131**(5): 657-633.
- 669 Gauthier S, Mausbach J, Reisch T *et al*. "Suicide tourism: a pilot study on the Swiss phenomenon". *J Med Ethics* 2015; **41**(8): 611-7.
- 670 "Conductor Sir Edward Downes and wife end lives at Dignitas clinic." *The Telegraph*, 14 July 2009. Available at: <http://www.telegraph.co.uk/culture/music/music-news/5823704/Conductor-Sir-Edward-Downes-and-wife-end-lives-at-Dignitas-clinic.html> (Accessed 2 December 2015).

- 671 Laurance J "Agony of helping a son to kill himself". *The Independent*, Sunday 23 October 2011. Available at: <http://www.independent.co.uk/life-style/health-and-families/health-news/agon-y-of-helping-a-son-kill-himself-2289710.html> (Accessed 30 November 2015).
- 672 BBC News Online. "Right-to-die activist Nan Maitland 'died with dignity'". *BBC News Online*, 4 April 2011. Available at: <http://www.bbc.co.uk/news/uk-12959664> (Accessed 30 November 2015).
- 673 Carrier D. "Man who killed himself at Dignitas explains decision in film". *The Guardian*, Tuesday 26 May 2015. Available at: <http://www.theguardian.com/society/2015/may/26/jeffrey-spector-assisted-dying-dignitas-tumour-paralysis-explains-decision> (Accessed 30 November 2015).
- 674 Donnelly L "Healthy retired nurse ends her life because old age 'is awful.'" *The Telegraph*, 2 August 2015. Available at <http://www.telegraph.co.uk/news/health/11778859/Healthy-retired-nurse-ends-her-life-because-old-age-is-awful.html> (Accessed 30 November 2015).
- 675 Pharaoh G "Why I'd rather die than get old". *The Sunday Times*, 2 August 2015. Available at: [http://www.thesundaytimes.co.uk/sto/news/uk\\_news/National/article1588630.ece](http://www.thesundaytimes.co.uk/sto/news/uk_news/National/article1588630.ece) (Accessed 30 November 2015).
- 676 "Cancer sufferer makes Dignitas trip to end his life". *BBC News Online*, 14 August 2015. Available at: <http://www.bbc.co.uk/news/uk-wales-33926042> (Accessed 30 November 2015).
- 677 Lewis P, Black I (2012) *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Commissioned by the Commission on Assisted Dying. Available at <http://www.commissiononassisteddying.co.uk/wp-content/uploads/2012/01/Penney-Lewis-briefing-paper.pdf> (Accessed 20 November 2015). p.7.
- 678 Lewis P, Black I (2012) *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Commissioned by the Commission on Assisted Dying. Available at <http://www.commissiononassisteddying.co.uk/wp-content/uploads/2012/01/Penney-Lewis-briefing-paper.pdf> (Accessed 20 November 2015).
- 679 Levene I and Parker M. "Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review". *J Med Ethics* 2011; **37**: 205-11.
- 680 Steck N, Junker C, Maessen M *et al*. "Suicide assisted by right-to-die associations: a population based cohort study". *International Journal of Epidemiology* 2014; **43**(2): 614-22.
- 681 Bosshard G "Switzerland" in Griffiths J, Weyers H, Adams M (eds.) (2008) *Euthanasia and Law in Europe*. Hart Publishing: Oxford. p.473.
- 682 Swiss Academy of Medical Sciences (2004, updated 2013) *Medical Ethical Guidelines: End-of-Life Care*. SAMS: Basel.
- 683 Swiss Academy of Medical Sciences (2014) *Physicians' attitudes to assisted suicide: Summary of results and response of the Central Ethics Committee*. Available at: <http://www.samw.ch/en/Ethics/The-end-of-life.html> (Accessed 2 December 2015).
- 684 Lewis P, Black I (2012) *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Commissioned by the Commission on Assisted Dying. Available at <http://www.commissiononassisteddying.co.uk/wp-content/uploads/2012/01/Penney-Lewis-briefing-paper.pdf> (Accessed 20 November 2015). p.23.
- 685 Brauer S, Bolliger C, Strub J "Swiss physicians' attitudes to assisted suicide." *Swiss Med Wkly* 2015; **145**: w14142.
- 686 Lewis P, Black I (2012) *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Commissioned by the Commission on Assisted Dying. Available at <http://www.commissiononassisteddying.co.uk/wp-content/uploads/2012/01/Penney-Lewis-briefing-paper.pdf> (Accessed 20 November 2015).

- 687 Gamondi C, Pott M, Payne S "Families' experiences with patients who died after assisted suicide: a retrospective interview study in southern Switzerland". *Annals of Oncology* 2013; **24**: 1639-44.
- 688 Bosshard G, Ulrich E, Bär W "748 cases of suicide assisted by a Swiss right-to-die organisation." *Swiss Med Wkly* 2003; **133**: 310-7.







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