

Improving analgesic use to support pain management at the end of life

March 2017



Contents

1	Background.....	2
2	Introduction.....	2
3	Analgesic use in palliative care.....	3
4	Barriers to accessing appropriate pain relief at the end of life.....	5
5	Developing effective services to support analgesic prescribing at the end of life.....	9
6	Education and training to support pain relief at the end of life.....	15
7	Supporting appropriate analgesic use in specific patient populations.....	17
8	Conclusion and summary of recommendations.....	20
9	Further resources.....	22
	Appendix 1 – Summary of analgesic drugs.....	23
	Appendix 2 – Palliative care strategies in the UK.....	24
	Acknowledgements	25
	References.....	26

Abbreviations

BMA	British Medical Association
WHO	World Health Organization
NICE	National Institute of Health and Care Excellence
BNF	British National Formulary
NHS	National Health Service
RCP	Royal College of Physicians
PHSO	Parliamentary Health Service Ombudsmen
CQC	Care Quality Commission
HEE	Health Education England
WIHSC	Welsh Institute for Health and Social Care
ELCPAD	End-of-Life Care and Physician Assisted Dying

This publication was prepared under the auspices of the BMA board of science. Approval for publication was recommended by BMA council on 24 March 2017.

We are grateful to the Faculty of Pain Medicine of the Royal College of Anaesthetists for their guidance in producing this document. A full list of contributors can be found in the Acknowledgements section at the end of this document.

1 Background

In 2016, the BMA published the findings of a comprehensive research project exploring patient and physician attitudes around end-of-life care.^{1,2,3} The results of this project indicated that pain was a leading concern identified by members of the public and doctors, when asked to consider fears about the end of life and dying. Despite this, the provision of adequate pain relief at the end of life – particularly access to strong opioid analgesics – has been identified as an area that requires improvement.² This briefing paper specifically considers the need to improve analgesic use to support pain management at the end of life. It sets out a range of recommendations for governments, policy makers and healthcare professionals, with the aim of promoting adequate access to analgesia for patients at the end of life. Although there has been an overall increase in the prescribing of opioid analgesics in recent years, there are separate and distinct issues surrounding the potential overuse of analgesics in patients suffering from chronic pain – these concerns are explored as part of a related BMA briefing paper *Chronic pain – supporting safer analgesic prescribing*.

Issues surrounding the appropriate use of analgesics are of wide relevance to BMA members across different branches of practice. This briefing follows a BMA board of science seminar in September 2014, initiated by Baroness Ilora Finlay (BMA president 2014-15), which explored problems facing clinicians when prescribing opioids in palliative care and for chronic pain.

2 Introduction

The number of people needing end-of-life care is expected to rise over the next 15 years.⁴ Controlling pain during this time is a central part of specialist palliative care. While the early development of palliative care focused on terminal cancer, there is growing awareness of the palliative care needs of all patients with terminal illness.⁵ Many of the patients who die each year from non-cancer illness suffer from circulatory, respiratory or neurological diseases that may necessitate the management of pain. The WHO's (World Health Organization) definition of palliative care has been broadened from its original emphasis on cancer, to one that encompasses all advanced life-threatening illness.^{5,6} There is now a greater recognition of the importance of symptom control, including pain relief, for all conditions, and analgesic use forms a crucial part of effectively managing a terminally ill patient's symptoms. Pain experienced by those with terminal illness may be as a result of the disease itself, disease treatment, or from co-morbid conditions.⁷ Psychological distress, commonly experienced by patients with advanced disease, may also impact on the perception of pain.⁷

The focus of this briefing is on promoting adequate access to pain relief for patients at the end of life, including exploring the attitudes of doctors and patients towards the prescribing of strong analgesics to control pain. As the management of pain is an essential component of specialist palliative care services, it also considers the provision of these services. This includes their commissioning and how to support referrals. There is also a need to support equity of access to pain relief for cancer and non-cancer patients, and issues related to the care of children, and patients with difficulty communicating their pain.

In light of concerns surrounding the lack of access to adequate analgesia at the end of life,³ it focuses on supporting improvements in this area, in particular the use of stronger analgesics, such as opioids. It should be noted that while opioids are often the mainstay of pain management in patients at the end of life, they may not always be effective in relieving pain, and other analgesics may need to be combined with opioids to improve pain outcomes. **Appendix 1** provides a summary of the various types of drugs that are used for the treatment of pain.

3 Analgesic use in palliative care

There is a need for improvements in pain management at the end of life in relation to access to specialist palliative care and associated services, of which pain relief is a core component.³

The Economist Intelligence Unit's Quality of Death Index 2015 rated the UK to be the best place to die of the 80 countries it considered. It based this conclusion on the assessment of a variety of factors, including the quality of care and the presence of national strategies.⁸ The UK ranked highly in all categories, although in common with the rest of the world, performed poorly in the capacity to deliver palliative care.^a This reflects concerns about the under-provision of palliative care services, and therefore access to adequate pain relief, with specific concerns over access for those patients with non-cancer terminal illnesses (see **Section 4.2**).

3.1 Opioid prescribing in palliative care

There has been a substantial increase in the overall number of opioid analgesics prescribed in recent years. The majority of this is attributable to their use in chronic pain, as shown by analysis of data from the Clinical Practice Research Datalink.⁹ General practice prescribing of opioids for cancer pain in the UK increased by only 1.7% annually from 2000-2008,¹⁰ and the under treatment of cancer pain, particularly at the end of life, remains a concern.¹¹

Research using the General Practice Research Database showed that patients in the last three months of life tended to receive an increase in prescriptions for non-opioid, weak opioid and strong opioid analgesics.¹² This was particularly true for younger patients, with the research indicating that access to analgesics varied with age, with a higher percentage of older patients receiving no analgesics in the last three months of life.¹² There is also significant under prescribing of opioids for elderly patients with cancer. Another recent study of 6,080 patients that died from cancer showed that only 48% had received a strong opioid before death, and in those that did, median treatment duration was 11 weeks. Older people (age over 75 years) were less likely to receive a strong opioid, and if they did, they were treated for significantly shorter duration before death than younger patients.¹³ Analysis of data from the National Survey of Bereaved People (VOICES) indicated that people aged over 60 receive less pain relief than younger patients, but also suggests that those over 80 may be more likely to have their pain relieved completely, all of the time, than those under 80. Though the authors of this analysis caution that this may be as a result of underreporting of pain.¹⁴

Recommendation: Steps should be taken to understand the barriers to prescribing opioids in palliative care and ensure that access to appropriate pain relief in palliative care is not affected by a patient's age.

3.1.1 Opioid prescribing for patients with non-cancer terminal conditions.

The provision of pain relief for patients with non-cancer terminal illnesses is difficult to determine, with only limited data available. Across different patient groups there has been little research on whether these patients receive adequate access to pain relief. Research does, however, demonstrate that only a small proportion of patients with non-cancer terminal illness (such as advanced neurological conditions) access palliative care services which are specialised in end-of-life pain relief.¹⁵

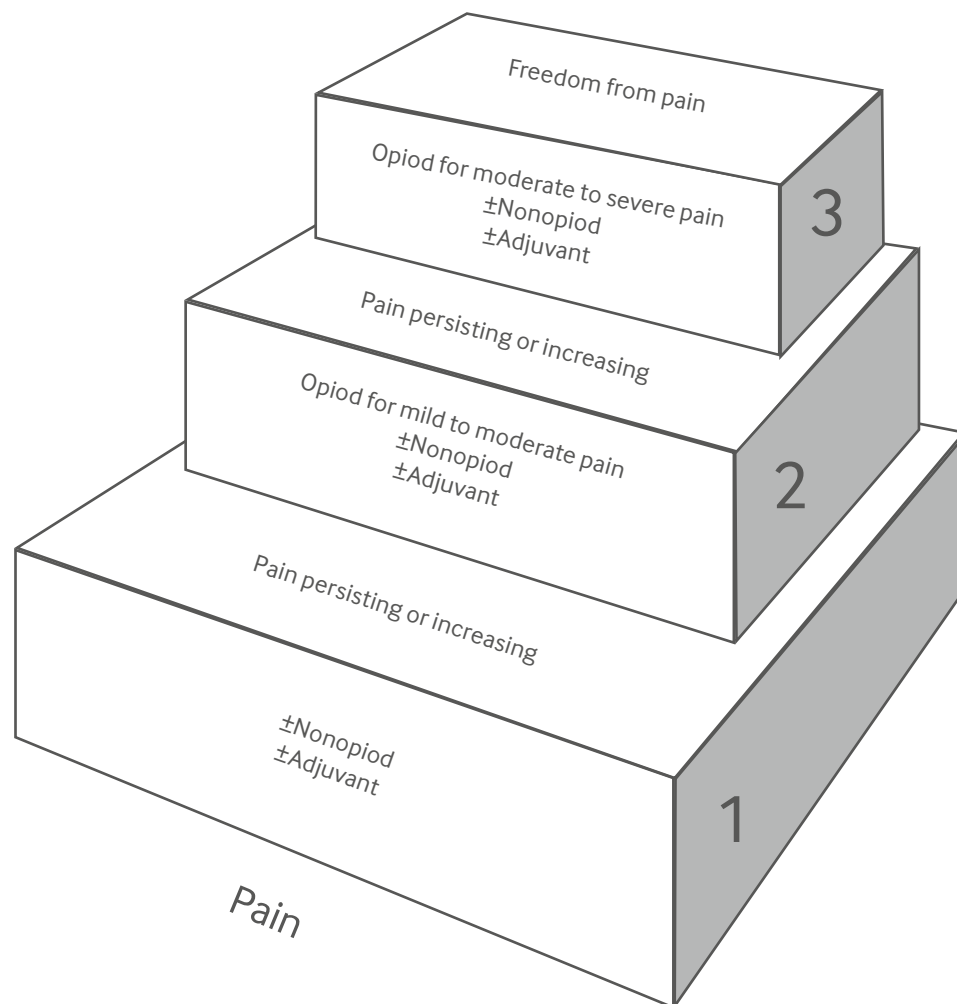
a Defined by the Economist Intelligence Unit as the proportion of people who died in a country in one year that would have been able to receive palliative care, given the country's existing resources.

Research conducted in Scotland found that, while over two-thirds of cancer patients had been formally identified for inclusion on their practice's palliative care register, this was just 20% for non-cancer patients.¹⁶ In England, patients with non-cancer diagnoses receive less specialist care and less generalist care than patients with cancer.¹⁴ Issues surrounding access to palliative care, including for people with non-cancer terminal conditions, are explored in more detail in **Section 5**.

3.2 Guidance on opioid prescribing in palliative care

There is a variety of guidance available on the prescribing of analgesics for patients in palliative care. One of the most prominent guidelines, and the basis for many others, is the WHO's analgesic ladder (see **Figure 1**). There are three stages to the ladder, corresponding to different levels of pain relief that are progressed to depending on the success of each stage. The first recommends a non-opioid, moving to a weak opioid (such as codeine, dihydrocodeine or tramadol) in conjunction with an adjuvant and non-opioid analgesic for moderate pain. If these are not effective, for severe pain, the WHO recommends the use of a strong opioid (such as morphine, methadone, oxycodone or hydromorphone) with an adjuvant and non-opioid analgesic.¹⁷ It is estimated that, combined with appropriate dosages, the WHO ladder should be sufficient to provide adequate pain relief in between 70% and 90% of patients receiving palliative care.¹⁸

Figure 1 – The World Health Organisation analgesic ladder



Source: WHO's cancer pain ladder for adults (available at: <http://www.who.int/cancer/palliative/painladder>)

Guidance by NICE (National Institute for Health and Care Excellence) is available on the safe and effective prescribing of strong opioids for the treatment of pain in palliative care.¹⁹ This highlights the importance of clear communication with patients, including talking to them about concerns regarding addiction, side effects and fears over the notion that starting strong opioids means they are entering the final stages of life. The Scottish Palliative Care Guidelines also provide comprehensive information on pain management at the end of life.²⁰ *Opioids aware* – a web-based prescribing resource funded by Public Health England and produced by the Faculty of Pain Medicine – has been developed.⁷ It provides a range of guidance to support opioid prescribing in different clinical settings, including for pain management in palliative care, and advocates adherence to NICE guidance in this setting. Guidance in the BNF (British National Formulary) on the general management of pain in palliative care reinforces the approach of the WHO. The BNF recommends that alternatives to morphine should be initiated by those with experience in palliative care. It also states that initiation of an opioid analgesic in palliative care should not be delayed over concerns of a psychological dependence and that the cautions it lists for opioid analgesics should not necessarily be a deterrent for their use in the control of pain in people with a terminal illness.²¹

4. Barriers to accessing appropriate pain relief at the end of life

Three categories of barrier have been suggested as preventing the appropriate control of pain at the end of life – system, professional and patient (See **Figure 2**).²² *System barriers* concern regulation of the use of opioids, or the inadequate provision of palliative care services; *professional barriers* include concerns about hastening death, insufficient experience of pain management, concerns about side-effects, fear of addiction; and *patient barriers* include a reluctance to report pain, fear of addiction to opioids, fear of side-effects and the idea that strong opioids means that they are near to the end of their life. The most frequently reported barriers by professionals to the treatment of cancer pain were inadequate assessment of pain and pain management, patient's reluctance to report pain, and inadequate knowledge of pain management.²³ The BMA's 2016 research project exploring patient and physician attitudes to end-of-life care emphasised the importance of timely access to medical services to support the provision of analgesics at the end of life, as well as appropriate systems that support access to the medications.³ The report also highlighted that it can be difficult for healthcare professionals to recognise when a patient is dying and to accurately predict how long they will live. This has led to recommendations that the individual teams and professionals involved in patient care should improve their ability to recognise when a patient is dying.^{1,3}

Figure 2 – Types of barrier to accessing pain relief at the end of life

Barriers	Examples
System	Regulation and guidance on the use of opioids Provision of palliative care services
Professional	Inadequate access to education and lack of relevant experience Concerns about side-effects, including hastening death, and addiction Inadequate assessment of pain and pain management
Patient	Concerns about treatment including fear of addiction and fear of hastening death Reluctance to report pain

Sources: Maltoni M (2008) Opioids, pain, and fear. *Annals of Oncology* **19**(1): 5-7 and Oldenmenger WH, Sillevius Smitt PAE, van Dooren S et al (2009) A systematic review on barriers hindering adequate cancer pain management and interventions to reduce them: a critical appraisal. *European Journal of Cancer* **45**: 1370-1380

4.1 Access to pain relief for patients with non-cancer terminal illness

Patients with non-cancer terminal illnesses are likely to experience poorer access to adequate pain relief than cancer patients, and available research indicates that cancer patients are more likely to receive palliative care than patients with other illnesses.^{15,16} A patient with advanced chronic obstructive pulmonary disease, for example, has poor access to specialist palliative care services, especially when compared to access for a patient with advanced lung cancer.²⁴ This may in part be due to the historical focus of palliative care, which has traditionally centred on the needs of patients with cancer.²⁵ Whereas improving access to palliative care for patients with non-malignant conditions has only recently been identified as a priority.²⁴

Determining prognosis for non-cancer terminal illness may be more challenging than for cancer as the nature of the diseases often make them less predictable. A 2005 systematic review – considering the timing of referral to palliative care and the tools available to assist decision making – concluded that referrals for non-cancer patients should not be based solely on a patient's survival prospects.²⁶ A range of physical, psychological and social factors may need to be taken into account.

There are further issues that make access to appropriate palliative care services difficult for patients with cognitive impairment. Despite evidence, for example, showing that palliative care can be beneficial for people with advanced dementia, they generally have poorer access to palliative and hospice care.²⁷ The prognosis for people with dementia is often uncertain, making it difficult to determine when they would most benefit from palliative care. Patients with cognitive impairments may also find it more difficult to communicate their pain to their doctor. The issues surrounding the difficulty of identifying pain in patients with impaired communication is explored in more detail in **Section 7**.

4.2 Attitudes of healthcare professionals towards the use of opioids in palliative care

The attitudes of healthcare professionals is an important factor affecting access to opioids in palliative care, in terms of the role they play in referring patients to services, as well as in decisions made about the prescribing of analgesics. There is evidence that concerns amongst doctors about the suitability of opioids may continue to influence prescribing at the end of life. A systematic review of the barriers to managing cancer pain concluded that between 34% and 86% of professionals overestimated the likelihood of addiction or tolerance when prescribing opioid analgesics at the end of life.²³ Fears about the potential for respiratory depression resulting in a patient's death, were also commonly cited as affecting decisions.²³ This underlines the importance of doctors having access to specialist support and advice.

4.2.1 Fears over hastening death

There is little evidence to suggest that the appropriate use of analgesics to control pain at the end of life hastens death. If analgesics are properly adjusted against a patient's pain, the risk of respiratory depression is small, and it is unlikely to have an effect on a patient's lifespan.¹ Despite this, there are concerns that administering strong analgesics at the end of life can, in some instances, hasten the death of a patient. The principle or doctrine of double effect has been used to justify the use of opioids to relieve pain in palliative care patients, even if there is a fear that they may lead to the unintended shortening of the patient's life through respiratory depression (see **Box 1**).

Box 1 – The principle of double effect

The BMA's *Medical Ethics Today* explains that the principle of double effect allows doctors to provide medical treatment that has both good and bad effects, as long as the intention is to provide an overall good effect.²⁸ The principle states that the administration of drugs that may hasten death is lawful and ethical when the patient is terminally ill and the use of the drugs is in their best interest, provided that the intention of the doctor is the alleviation of suffering, and not the hastening of death. The principle has become prominent enough to have been used as a legal defence for doctors facing charges of murder when administering opioids and has been referred to by House of Lords select committees.²⁹

In a 2003 review of evidence on the effects of opioids on survival, it was concluded that none of the available research demonstrated that opioids, prescribed to relieve pain, lead to a shortening of life.³⁰ A more recent 2013 systematic review, considering several additional studies, concluded that all available studies into opioid use and patient survival indicate that their use for symptom control in advanced disease does not shorten a patient's life.³¹ In this review higher doses and double doses at night were not found to have an impact on survival. In some cases, the use of higher opiate doses was associated with longer survival.³¹

Key message

The available evidence indicates that, when used appropriately, strong opioids prescribed to relieve pain at the end of life do not hasten death

It has been proposed that the principle of double effect may reinforce the idea that adequate symptom control at the end of life can hasten death, thereby dissuading some doctors from administering opioids.^{30,32} However, it may be useful for reassuring healthcare professionals who are more apprehensive about the use of opioids. It has also been used to differentiate, legally and ethically, between the legitimate use of strong opioids to relieve pain and symptoms at the end of life, and the illegitimate use of such medication with the intention of hastening death.

A study conducted in 2012 – which collected the views of 31 health professionals through four focus groups – found that concerns remain about prescribing opioids such as morphine to patients near the end of life because of fears of respiratory depression.³³ There is some evidence to suggest that attitudes towards opioids, and their risks to patients, are changing. For example, the number of deaths in the UK in which doctors thought life had been shortened as a result of double effect decisions fell from 32.8% in 2004 to 17.1% in 2008, despite no reduction in the use of opioids.³⁴ There was a marked difference depending on the place of treatment and the specialty of the doctor, with particularly low rates reported by palliative care specialists and for deaths in care homes and hospices, and higher rates reported for deaths in the patient's own home or in hospital.³⁴ This suggests that while specialists are aware of the appropriate use of opioids at the end of life, more could be done to ensure that non-specialists responsible for providing palliative care receive the necessary training on prescribing opioid analgesics.

These trends have also been observed outside of the UK. A study on the use of opioids by physicians in the Netherlands found that the number who thought that they were hastening the death of their patients has dropped over time, and the data did not suggest that they had reduced the dosages of opioids they were using.³⁵ This led the authors to conclude that physicians were becoming more aware of the limited life-shortening effects of opioids when prescribed appropriately.

4.2.2 Impact of the Harold Shipman case

The Shipman murders – in which the GP Harold Shipman killed potentially upwards of 215 patients with lethal doses of diamorphine – have been suggested as having had an effect on the prescribing of opioids, potentially resulting in their underuse.³³ In a small survey of 90 GPs and 27 senior hospital doctors carried out in 2005, 46% expressed reservations about using opioids for terminally ill patients due to the concerns raised following the Shipman murders.³⁶ It also found that, while most were prepared to prescribe as much as necessary to control cancer pain, 25% said they would avoid opioids or minimise their use. The BMA's end-of-life care report also highlighted concerns about the impact the media coverage of the Shipman case may have had on doctors' confidence to prescribe strong analgesics.² Separately, some GPs have expressed apprehension about prescribing opioids to palliative care patients following Shipman's conviction and may appreciate the input and opinions of specialists, such as those working in hospices or Macmillan nurses.³³ Despite some concern expressed by doctors, there is little published research on the effect the Shipman case has had on palliative care in the UK.¹

Recommendations:

- Anxiety amongst healthcare professionals about administering high, but appropriate, levels of strong analgesics and sedatives, to patients at the end of life should be addressed.
- Generalists responsible for treating pain at the end of life should routinely ask about the presence and severity of pain, and have access to advice and support from specialists.

4.3 Patient attitudes towards the use of analgesics in palliative care

Patient attitudes towards opioid treatment may also influence access to effective pain management in palliative care. A 2009 systematic review concluded that patients may impede their own treatment due to misconceptions about analgesic treatment, non-adherence to treatment regimens and poor communication with doctors.²³ A separate 2009 pan-European study of cancer-related pain found that 12% of patients in the UK thought that their healthcare provider did not understand that pain was a problem.³⁷

The way in which doctors communicate the start of strong opioid treatment can have a significant influence on the patient's attitude towards the treatment. Based on the findings of an in-depth interview study of 18 cancer patients, the main factors considered by patients when deciding whether to start opioid treatment were: professional competence, the manner of communication, and a doctor-patient relationship based on trust.^{22,38} NICE guidance on the prescribing of opioids in palliative care identifies several barriers to successful opioid treatment that relate to communication between patients and prescribers. It identifies concerns over addiction, developing tolerance and side effects, reluctance from the patient to focus on pain management rather than attempting a cure, and the relationship between opioid treatment and the severity of the illness.¹⁹ There is an important role for doctors in having clear discussions with patients about what they are expecting analgesics to achieve, which is likely to focus on the management of pain whilst maintaining function, rather than being completely pain free.¹

5 Developing effective services to support analgesic prescribing at the end of life

Improved access to and availability of specialist palliative care services – of which pain relief is a key component – would help reduce the burden of pain for those near the end of life. The PHSO's (Parliamentary and Health Service Ombudsman) 2015 report into end-of-life care highlighted that concerns remain about the services available in England, and that poor symptom control was leading to patients dying in pain.³⁹ In Scotland, a report prepared for the Scottish Parliament's Health and Sport Committee indicated that 10,600 people may die each year without accessing palliative care from which they could have benefited.⁴⁰ Research carried out by the London School of Economics and commissioned by Marie Curie estimated that 6,200 patients miss out on referral to palliative care services each year in Wales,⁴¹ and 3,000 in Northern Ireland.⁴² In reviewing the implementation of the palliative and end-of-life care strategy in Northern Ireland, the RQIA (regulation and quality improvement authority) highlighted the management of symptoms, including pain, as a key component.⁴³

As previously highlighted, the BMA's project on end-of-life care indicated that dying in pain was a key concern to members of the public.² This supports a 2011 survey indicating that the greatest fear people in the UK have about dying is dying in pain.⁴⁴ While many patients receive adequate care, there are some who do not have their pain controlled, or are not identified as requiring palliative care services. Research into palliative care experiences in London found that the majority of patients receive palliative care from generalists, either through GPs or district nurses, and GPs remain the first point of contact for most patients, including those who are eventually referred onto specialist palliative care services.⁴⁵ With patients more likely to receive adequate pain relief when under the care of a specialist, improving the identification of patients with palliative care needs, and supporting generalists to provide more effective pain relief, are vital steps to securing better care for patients near the end of life. This necessitates improved access to specialist support and advice (see **Section 6**).

Key message

Pain is a key fear/concern that people in the UK have about dying. Improved access to and availability of specialist palliative care services would help reduce the burden of pain for those near the end of life.

5.1 Specialist palliative care services

Specialist palliative care services include in-patient facilities, support for generalists providing community and in-hospital care, and coordination of services.¹ Whilst palliative care teams exist in all NHS trusts and health boards across the UK, the funding for these teams varies significantly across regions, as does access to specialist palliative care teams.^{46,47} Access to round the clock pain relief provided by specialist palliative care teams is therefore patchy across the UK.³ A 2016 report by the RCP (Royal College of Physicians) further highlighted wide variation in the availability of specialist palliative care teams in hospitals in England.⁴⁸

The setting in which a patient receives their care may affect the degree of pain relief that they receive. A 2014 Marie Curie report – evaluating experiences of dying cancer patients across the UK – found that poor access to pain relief is a significant problem for cancer patients living in the community.⁴⁹ The report also found that poor anticipatory prescribing of analgesia, inefficient out-of-hours services and uncoordinated care, were all key barriers to achieving timely access to pain relief for cancer patients dying at home.⁴⁹

A 2012 study of patients' preferred place of death found that 64% of patients in England would prefer to die in their own home or the home of a friend or relative.⁵⁰ The 2013 National Survey of Bereaved People, (VOICES) conducted in England, highlighted that pain relief for those receiving end-of-life care in their own home is poorer than for those receiving end-of-life care in a hospice. Only 18% of respondents felt that their relative received adequate pain relief from their end-of-life care at home in comparison to 62% in hospices.⁵¹ This is supported by further research considering the effect of different care settings on pain relief. A comparison in Scotland – of the time taken for pain to be controlled between patients managed in the community by GPs and those managed by a specialist palliative care service in a hospice – found significant differences. Whilst 30% of patients in the hospice achieved good pain control within four days, only 3% achieved it amongst patients managed in the community.⁵²

Recommendation:

- Organisations responsible for commissioning and providing palliative care services should ensure that specialist palliative care services are available to all patients with palliative care needs, including in their own homes, hospices, care homes and elsewhere in the community.

5.2 National strategies for palliative care services

Strategies for the provision of palliative care services have been published by each of the nations in the UK within the last five years (see **Appendix 2**). All of these recognise that there is unmet need and that a variety of actions will be required to improve access to palliative care. There remain issues surrounding access to adequate pain relief and patients continue to suffer unnecessarily from pain at the end of life. Furthermore, there is still work to do on supporting palliative care for non-cancer conditions. It is hoped that, in improving access to palliative care services across the country, the number of patients who suffer unnecessarily from pain at the end of life will be minimised. To achieve this, a focus is needed on supporting patients being treated in the community, on supporting their referral to specialist services, and a specific focus on improving access to appropriate services for patients who have non-cancer conditions.

Key message

Although each of the four nations of the UK have national strategies for palliative care services, there remain issues surrounding access to adequate pain relief and patients continue to suffer unnecessarily from pain at the end of life.

Recommendation:

- Comprehensive guidance should be provided so that doctors are better able to identify and refer patients with non-cancer terminal illness to specialist palliative care services. This should be supported by nationally agreed criteria for accessing specialist palliative care services.

5.3 Supporting referrals to specialist palliative care services

There are currently no nationally agreed criteria for accessing specialist palliative care services.⁵³ According to the National Council for Palliative Care, a good service should have a written referral criteria, which should include that:

- the patient has progressive, advanced disease, where treatment has moved from being curative or where no cure is available;
- the patient has needs that cannot be met elsewhere; and
- the patient provides consent where possible.

Central to securing referrals to specialist palliative care services is ensuring timely identification of those patients who are approaching the end of their lives, and require referral to such services.³ The PHSO's report into end-of-life care in England also highlighted this, suggesting that the NHS needs to improve in recognising when patients have palliative care needs.³⁹ A study in 2016 of 4,650 patients referred to specialist palliative care services showed that the median referral time before death was 34 days. Patients with cancer received a median of 37 days of care compared with a median of 16 days for patients with non-cancer diagnoses. Older patients (>75) received a median 29 days compared to 55 days for those under 50 years of age. These data highlight the relatively late referral to palliative care services, particularly for older patients and those with non-cancer terminal illnesses.⁵⁴

Key message

Central to securing referrals to specialist palliative care services is ensuring timely identification of those patients who are approaching the end of their lives, and require referral to such services.

A 2015 Marie Curie report on access to palliative care for patients with non-cancer conditions identified a number of areas for improvement. In relation to achieving improved referral processes, it suggested targeted training and education, and the use of appropriate referral criteria, as ways of supporting earlier access to palliative care.²⁷ It also suggested that a prognosis-based approach to palliative care referrals is inappropriate for many terminal conditions. Instead it recommends using appropriate triggers, and a more dynamic approach due to the fluctuating nature of some conditions. The triggers include when someone has:

- a complex or persistent problem;
- high levels of unplanned hospital use;
- one or more condition to manage;
- changes to eating habits;
- new clinical interventions introduced;
- been diagnosed with a particular condition; and
- high levels of palliative care needs as indicated by a screening tool.

Supporting GPs with the use of these triggers, and ensuring that there is consistency in the referral criteria and processes for local specialist services, may help to improve the identification of patients who could benefit from palliative care, and therefore enable them to access appropriate pain relief towards the end of their lives.

5.3.1 Focus on improving access to specialist services for non-cancer terminal illness

As identified in **Section 4**, access to specialist palliative care services is particularly problematic for patients who have non-cancer terminal illnesses. While the same challenges and barriers are present as for cancer conditions, there may be additional obstacles that prevent these patients from being referred to specialist services. Some of the barriers that have been suggested include:

- the greater difficulty identifying when a non-cancer condition is in a terminal stage, and predicting the trajectory of these conditions;
- a lack of expertise on the condition;
- poor co-ordination between healthcare professionals;
- insufficient resources; and
- communication difficulties.¹³

Each of the UK's national palliative care strategies acknowledge that non-cancer terminal conditions do not benefit from the same degree of access to services. For instance, Northern Ireland's palliative care strategy notes that services have not always been designed to be responsive to non-cancer conditions, due to a lack of comprehensive information about palliative care needs. It has therefore called for more effective information systems that will inform future commissioning, based on qualitative and quantitative data on individual and community needs. In addressing the disparity in access to palliative services, it is important to recognise the need for palliative care in patients with dementia. However, there are added complications when a patient with dementia is unable to adequately communicate that they are in pain. The specific difficulties surrounding pain in individuals with communication difficulties will be explored more fully in **Section 7**.

While national palliative and end-of-life care strategies now consider the needs of non-cancer patients, a more explicit effort is required to address the inequalities in access that currently exist, and ensure adequate access to pain relief for these patients. More research is needed into the care and treatment available for patients with non-cancer conditions, and to enable better diagnosis of palliative care need in these patients.²⁷ In addition, greater support is needed for doctors treating patients with non-cancer conditions, to help them to diagnose, manage and appropriately refer to specialist services.

Recommendation:

- More research should be conducted to specifically assess the access to pain relief for patients with non-cancer terminal illnesses.

5.4 Community pharmacy and non-medical prescribing

There is a need to consider the role of community pharmacy and non-medical prescribing in supporting access to, and management of, pain relief for patients at the end of life. This includes through the prescribing of analgesics, as well as the development of systems and infrastructure that ensure patients have physical access to analgesic medication when required.⁵⁵ Over recent years, community pharmacists have moved away from predominantly dispensing medicines, to increasingly providing clinical services (including, for example, new medicines services and medicines use reviews).⁵⁶ Since 2012, non-medical prescribers – including specialist nurses and pharmacists – have been able to prescribe controlled drugs, such as opioids. This aims to improve access to these medications, which may support provision of pain relief in the community for patients at the end of life.⁵⁷ It has, however, been suggested that growth in non-medical prescribing in the UK, has outpaced research to understand and evaluate its benefits; and more research is required to assess the effectiveness of increasing numbers of non-medical prescribers in improving access to analgesics at the end of life.⁵⁷

5.5 Supporting organisational and cultural change to improve pain relief at the end of life

With the number of people needing end-of-life care expected to rise over the next 15 years,⁴ it is likely that more of this care will be provided in the community and by primary care professionals. It is therefore important to consider the actions that can be taken to support GPs and nurses providing palliative care in primary care settings. In the PHSO's report, *Dying without dignity*, the Ombudsman concluded that while palliative care specialists are often comfortable in their use of opioids, there remains scope for further support for their use in generalist settings.

The BMA's report on end-of-life care highlighted the need for healthcare professionals to be better supported at having discussions about end of life care with patients and their families.³ This may, for example, include exploring issues around the management of pain. Guidance and additional training in communication and listening skills are identified as important paths to achieving this. The Welsh strategy for palliative care services sets out the need for easier access to specialist advice for generalists responsible for palliative care in the community. This is echoed in Northern Ireland's *Living matters: dying matters* which explains that generalist staff should have access to education and training about palliative and end-of-life care, and access to specialist advice services.

Doctors should be encouraged to seek advice when prescribing analgesics, and the services required to provide that support need to be more widespread. There are also a number of organisational issues that need to be overcome in order to improve access to appropriate palliative care services and to ensure that pain is controlled. A 2016 RCP audit of end-of-life care highlighted that out-of-hours palliative care services need to be enhanced,⁵⁸ with the PHSO report also identifying several cases where these were considered to be inadequate.³⁹ In a survey of provider organisations conducted by the National Council for Palliative Care, 57% of respondents reported that there were gaps in access to specialist palliative care, and 49% thought that there was no 24 hour access to pain relief in their local area.⁵⁹ There is also a need to ensure access to analgesic medications, especially in community and out-of-hours settings, and appropriate systems need to be in place to ensure appropriate and timely availability of analgesic drugs.² Improvements in these services also requires greater adherence to guidance on the appropriate handover of patients. This is to ensure that healthcare professionals involved in treating a patient that has been discharged from hospital in the community, such as GPs and community nursing teams, are properly informed of the required care.^{3,60}

Key message

It is vital that community and primary care services are adequately resourced to ensure GPs are able to continue providing pain relief for the majority of palliative care patients, and act as effective gatekeepers to specialist services.

Additional education and training for GPs responsible for providing out-of-hours palliative care would also be beneficial, and is explored in more detail in **Section 6**. In light of the greater proportion of older people that the population will contain in the future, it will be vital for primary care to be adequately supported if GPs are to continue providing pain relief for the majority of palliative care patients, and act as effective gatekeepers to specialist services. This will require matching the funding and resources available to primary care with the demands placed on it, to provide primary care staff the opportunity to spend more time with patients, and support continuity of care.

The Faculty of Pain Medicine has developed *Core Standards for Pain Management Services* that include a section on cancer-related pain (see **Box 2**).⁶¹ The CQC (Care Quality Commission) inspection framework for end-of-life care services includes specific questions about implementation of these standards.⁶²

Box 2 – Faculty of Pain Medicine – Core Standards for Pain Management Services (2015)Standards for cancer-related pain:

1. Patients with cancer-related pain must receive a pain assessment when seen by a healthcare professional, which at a minimum assesses the cause, intensity and the impact of any pain that they report.
2. Access to analgesia must be available within 24 hours following a pain assessment which directs the need for analgesia. This must include access to a prescriber as well as access to a dispensed prescription.
3. Patients and carers must receive adequate information on the use of analgesics, especially strong opioids (in accordance with NICE guidance on *Opioids in Palliative Care*). This must cover how to take analgesia, the likely effectiveness of this, how to monitor side effects, plans for further follow-up, and how to get help – especially out of hours.
4. Patients and carers must be referred for specialist support if pain is not well controlled despite initial management. Specialist support must be available in each region in the form of palliative care services, oncology services (including radiotherapy), and specialist pain services

Recommendations:

- Health departments across the UK should ensure that specialist palliative care advice is available whenever and wherever the need arises.
- Systems need to be in place, in all areas, to ensure appropriate and timely availability of medication and equipment, particularly for those being cared for in the community.

6 Education and training to support pain relief at the end of life

6.1 The need for training

The education, training and support requirements of healthcare professionals providing palliative care have been explored in detail over the last few years, and there has been recent recognition of its importance as part of the growing focus on palliative care needs;⁶³ including as part of the BMA's recent research project on end-of-life care.³ It is important that this complements a greater focus on pain relief in medical schools, a central part of which should include the vital role of pain relief and the appropriate use of analgesics for patients receiving palliative care.

Additional training, education and support may specifically be required to overcome some of the remaining concerns amongst healthcare professionals. This is particularly relevant to those who are not palliative care specialists, in relation to the possibility of opioid use hastening death, as explored in **Section 4**. There remains a need to tackle the perception that opioids can hasten death in a patient even when they are used appropriately.

Additional training in palliative care for generalists is likely to support substantial improvements in analgesic use. There are two broad aspects that are required to support improved prescribing:

- to aid doctors in the identification of patients' palliative care needs, including pain relief; and
- to provide doctors with the knowledge and guidance to support appropriate prescribing and use of analgesics for palliative care patients in order to effectively manage their pain.

The 2015 Marie Curie report, *Triggers for Palliative Care*, specifically identified targeted training and education as a way of supporting earlier access, and its Chief Executive has suggested that palliative care and end-of-life training should be a priority for all health and social care professionals.^{27,64} The PHSO's report, *Dying without dignity*, also suggests that additional guidance and training in communication skills would serve to help doctors have better discussions about end-of-life care with patients and families.³⁹ Research into educational needs and preferences of GPs providing out-of-hours palliative care found that there was a lack of confidence in a range of key palliative care skills.⁶⁵ One of the areas of education that the GPs in the study expressed a preference to receive more of was symptom control in non-cancer patients.

6.2 Introducing additional education and training

The BMA's series of reports on end-of-life care explored, in detail, the range of education and training required to support improvements in the provision of palliative care.³ A key aspect of this area is to ensure all those involved in clinical care are aware of end-of-life issues, including the provision of adequate pain relief.

The BMA supports calls for HEE (Health Education England) to require all providers to ensure that all healthcare professionals are trained in the importance of pain control.⁶⁶ Those responsible for training healthcare professionals should ensure that the importance of pain control is appropriately included in relevant training, as part of undergraduate and postgraduate curricula and national vocational courses.

Continued professional development and ongoing training in palliative care would also ensure that generalists as well as palliative care specialists are able to provide the most appropriate treatment to patients, and would support improvements in analgesic prescribing. Research consisting of eight focus groups, four interviews and surveys of palliative care need at two hospitals identified some of the most successful models for

delivering additional education and training to healthcare professionals that may be involved in the provision of palliative care.⁶⁷ These included:

- study days for care home staff;
- practice-based education and decision-making support for GPs;
- educational inductions for palliative partnership models involving GPs and practice nurses; and
- shared learning practices involving specialists and generalist.⁶⁷

Recommendations:

- Those responsible for medical education and training should ensure that the importance of pain control is appropriately included in relevant training, as part of university undergraduate and postgraduate medical curricula.
- Additional specific training in palliative care should be provided as a core part of specialty training programmes, to support improvements in analgesic use.

6.3 Access to specialist support and advice

Doctors providing palliative care should be able to identify when specialist support is required and be able to access such support when necessary. Improving access to specialist pain advice for generalists responsible for the treatment of patients' pain is important for supporting improvements in the use of analgesics, and therefore a patient's experience of pain at the end of life. There has been some progress on this around the UK. The Welsh Government's palliative care strategy set as one of its priorities for local health boards to provide information to generalist teams informing them on how to access support from specialist palliative care services. Northern Ireland's strategy, *Living Matters Dying Matters*, states that specialist palliative care advice should be available across all care settings 24 hours a day, and that out-of-hours teams should be competent to provide advice to family carers and staff across all community care settings. These efforts should be continued, and should be repeated across the whole of the UK, with advice services made available for GPs, district nurses and other generalists responsible for the provision of pain relief at the end of life. Guidance published collaboratively – by the Association for Palliative Medicine, the Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, the National Council for Palliative Care, and the Palliative Care Section of the Royal Society of Medicine – recommends that there should be 24 hour access to specialist palliative care advice, which should be delivered by telephone as a minimum.⁵³

Whilst guidance has been produced on the use of analgesics for the management of pain in palliative care settings (see **Section 3.2**), to ensure the relief of pain is seen as a clinical priority there is a need for a renewed emphasis on the utilisation of this guidance, and the development of tools to assist healthcare professionals when prescribing analgesics for patients at the end of life.

Recommendation:

- Existing guidance on the appropriate prescribing of analgesics in palliative care needs to be promoted, this should include reviewing the impact of existing prescribing guidance and how this can be maximised to support more appropriate use of analgesics in different settings.

7 Supporting appropriate analgesic use in specific patient populations

There are some patient groups that, when considering ways to support improvements in analgesic prescribing, warrant separate and explicit consideration. This section considers two such groups; children, and those with impaired communication. It explores the different needs these groups have and the ways in which the provision of pain relief can be better supported.

7.1 Providing pain relief in children's palliative care

The provision of analgesics for children receiving palliative care requires specific consideration, as some of the treatment approaches may differ from those for adults. The charity Together for Short Lives have produced specific guidance on symptom control for paediatric palliative care, which includes guidance on the management of pain.⁶⁸ There is a variety of guidance available covering palliative care treatment for children, and NICE have recently published guidance on end-of-life care for infants, children and young people.⁶⁹

It has been suggested that a lack of access to specialist services for children's palliative care has meant that good symptom control is difficult to achieve. A 2015 WIHSC (Welsh Institute for Social Care) report made a number of recommendations, including some that are relevant across the UK. This included implementing a 24/7 specialist telephone service to provide advice to healthcare professionals, and that this could be developed nationally by working with the other nations of the UK.⁷⁰ It also called for an exploration of how information, learning and research can be shared nationally and internationally. The need for children's palliative care to be considered as a central part of end-of-life services is also reflected in NHS England's palliative care development currency, which considers both adult and child palliative care services.⁷¹ It is likely that an individual GP will be involved in the care of a child with a terminal illness only rarely during a career, underlining the importance of ensuring timely access to services specialist in providing this care.

Together for Short Lives have also highlighted significant variation in the care provided to seriously ill children in the UK;⁷² and that 4 out of 5 (81%) local authorities are failing to plan and fund care for children and young people with life-shortening conditions.⁷² The charity has produced best practice guides, commissioning guidance, a charter for services to display to demonstrate their commitment to the most important principles of child palliative care, along with additional resources for healthcare professionals and the families of children in palliative care.

In addition to the considerations to be taken into account when tailoring children's pain treatment, it is important that the child or young person's and family's expectations and preferences regarding pain management are explored and responded to appropriately.

Recommendation:

- To support the provision of pain relief specialist palliative care services tailored to the needs of children should be readily accessible in all parts of the UK.

7.2 Supporting the use of analgesics in patients with impaired communication

Assessment of pain in people with impaired communication, for example those with learning disabilities, can often be challenging.⁷⁷ The confidential inquiry into premature deaths of people with learning disabilities recognised that there are difficulties in identifying pain and communication difficulties for people with learning disabilities who have been admitted to palliative care.⁷³ The inquiry recommended that palliative care leads should work with specialist learning disability teams and learning disability champions to improve the care received.⁷³ This message is supported by the charity Help the Hospices, who also recommend a partnership of palliative care and learning disability specialists. It has been highlighted that relatively few people with learning disabilities receive pain relief and palliative care.⁷⁴ Ensuring that they do will become increasingly important, as the number of people over 60 living with learning disabilities is rising and has been predicted to grow by 36% between 2011 and 2021.⁷⁴

7.2.1 Identifying pain relief needs in patients with impaired communication

There are some tools available to assist in the diagnosing of pain in people with learning disabilities. DisDAT, the Disability Distress Assessment Tool, is intended to identify distress cues in people who have limited ability to communicate their own situation, and to document their usual cues to make it easier to identify these instances.⁷⁵ The Royal College of Nursing has produced guidance on dignity in care for patients with learning disabilities that is useful for all health and social care staff and includes advice on how to communicate with patients. For example, it recommends considering the use of pictures, photographs and symbols.⁷⁶ Furthermore, NICE is currently developing guidelines for the care and support of older people with learning disabilities, which are due to be published in October 2017.

Further best practice, advice and guidance on pain relief for those with impaired communication has been produced by a number of organisations. Mencap has produced best practice guidance for end-of-life care for people with learning disabilities, which highlights the important role of communication in assessing and treating pain and providing effective end-of-life care.⁷⁷ It also raises the issue of diagnostic overshadowing, where the label of learning disability can lead to healthcare professionals overlooking symptoms of ill-health, and recommends the use of tools such as DisDat, to help assess pain and distress.

Guidance by NICE on the care of the dying adult includes mention of assessing pain in a patient who cannot verbally communicate this, for instance, due to dementia or learning disability.⁷⁸ It recommends that a validated behavioural pain assessment tool is used to inform the management of these patients. In 2007, the RCP, British Pain Society and British Geriatrics Society produced guidance on the assessment of pain in older people, which makes particular reference to the challenges of impaired communication.⁷⁹ It lists a variety of tools that can be used to help identify patients in pain through behavioural changes. These include the Doloplus-2 scale, for behavioural pain assessment, the PAINAD (Pain Assessment in Advanced Dementia) scale, and the Abbey pain scale, for people with dementia who cannot verbalise. The guidance identifies the main observations used by the tools as:

- physiological observations, for example, sweating or breathing patterns;
- facial expressions, such as grimacing;
- body movements, for example, altered gait;
- verbalisations or vocalisations, such as groaning or screaming;
- changes in interpersonal interactions, for example, aggression or withdrawal;
- changes in activity patterns, such as altered sleep or wandering; and
- mental status changes, such as crying or irritability.⁷⁹

Ensuring the widespread use of these tools could help to treat pain more effectively amongst those who cannot easily communicate their pain. Identifying the need for pain relief is a substantial challenge to overcome in this patient group, and measures to improve diagnosis are an important step to increasing the proportion who receive adequate treatment.

Recommendation:

- All healthcare professionals and carers who are likely to come into contact with patients who may be unable to communicate pain should be trained in recognising the signs or have access to the advice and tools that can support their work.

8 Conclusion and summary of recommendations

- Whilst there is a growing appreciation of the pain-relief needs of patients at the end of life, there remains a clear need to convert awareness of the issues surrounding the provision of analgesics into meaningful actions. These should ensure that a patient's experience of pain is seen as a clinical priority that needs to be investigated and addressed.
- There is ongoing variation in the provision of, and funding for, specialist palliative care service across the UK; problems associated with lack of access to palliative care services and pain relief for those with non-cancer terminal illness persist; and the attitudes of healthcare professionals and patients may continue to act as a barrier to the appropriate prescribing of strong analgesics to relieve pain at the end of life.
- Successful prioritisation of pain relief necessitates action in a number of areas, including: service provision; training, continued education and professional development; and the development of guidance and supporting research.
- Recommendations set out in this briefing paper are intended to complement the BMA's existing work on end-of-life care,^{1,2,3} setting out a range of action areas to specifically support improved access to appropriate analgesia at the end of life. It is hoped that successful implementation of these recommendation will help provide a situation where all patients requiring palliative care are able to receive the analgesia necessary to control their pai

Summary of recommendations

Opioid prescribing

- Steps should be taken to understand the barriers to prescribing opioids in palliative care and ensure that access to appropriate pain relief in palliative care is not affected by a patient's age.
- Existing guidance on the appropriate prescribing of analgesics in palliative care needs to be promoted, this should include reviewing the impact of existing prescribing guidance and how this can be maximised to support more appropriate use of analgesics in different settings.

Access to services

- Organisations responsible for commissioning and providing palliative care services should ensure that specialist palliative care services are available to all patients with palliative care needs, including in their own homes, hospices, care homes and elsewhere in the community.
- Comprehensive guidance should be provided so that doctors are better able to identify and refer patients with non-cancer terminal illness to specialist palliative care services. This should be supported by nationally agreed criteria for accessing specialist palliative care services.
- More research should be conducted to specifically assess the access to pain relief for patients with non-cancer terminal illnesses.
- Systems need to be in place, in all areas, to ensure appropriate and timely availability of medication and equipment, particularly for those being cared for in the community.
- To support the provision of pain relief specialist palliative care services tailored to the needs of children should be readily accessible to people living in all parts of the UK.

Supporting healthcare professionals

- Anxiety amongst healthcare professionals about administering high, but appropriate, levels of strong analgesics and sedatives, to patients at the end of life should be addressed.
- Generalists responsible for treating pain at the end of life should have access to advice and support from specialists.
- Health departments across the UK should ensure that specialist palliative care advice is available whenever and wherever the need arises.

Education and training

- Those responsible for medical education and training should ensure that the importance of pain control is appropriately included in relevant training, as part of university undergraduate and postgraduate medical curricula.
- Additional specific training in palliative care should be provided as a core part of specialty training programmes, to support improvements in analgesic use.
- All healthcare professionals and carers who are likely to come into contact with patients who may be unable to communicate pain should be trained in recognising the signs or have access to the advice and tools that can support their work.

9 Further resources

Please note: this listing of publications is intended for further information only. The BMA is not responsible for the content or accuracy of external websites, nor does it endorse or otherwise guarantee the veracity of statements made in non-BMA publications.

Core Standards for Pain Management Services in the UK (2015) –

Faculty of Pain Medicine

Available at: <http://www.rcoa.ac.uk/system/files/FPM-CSPMS-UK2015.pdf>

End-of-life care and physician-assisted dying, Vol's 1-3 (2016) –

British Medical Association

Available at: <https://www.bma.org.uk/endoflifecare>

Dying without dignity (2015) – Parliamentary and Health Service Ombudsman

Available at: www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/1

Living and dying with dignity: The best practice guide to end-of-life care for people with a learning disability (2009) –

Mencap

Available at: www.mencap.org.uk/sites/default/files/documents/2009-04/best_practice_guide.pdf

Guidance on the management of pain in older people (2013) –

British Geriatrics Society

Available at: http://www.bgs.org.uk/pdfs/pain/age_ageing_pain_supplement.pdf

Appendix 1 – Summary of analgesic drugs

Summary of different analgesic drugs	
Analgesic type	Examples
Simple non-opioid analgesics	paracetamol, aspirin
NSAIDs (nonsteroidal anti-inflammatory drugs)	ibuprofen, naproxen, diclofenac, celecoxib, mefenamic acid, etoricoxib, indometacin
compound analgesics	co-codamol (codeine and paracetamol), co-dydramol (dihydrocodeine and paracetamol), co-codaprin (codeine and aspirin)
weak opioid	codeine, dihydrocodeine, meptazinol
strong opioid	morphine, buprenorphine, fentanyl, methadone, oxycodone, tapentadol, tramadol
drugs with anti-epileptic action	Carbamazepine, pregabalin, gabapentin
tricyclic antidepressants	amitriptyline, nortriptyline
selective serotonin reuptake inhibitors	fluoxetine
serotonin-noradrenaline reuptake inhibitors	duloxetine

Source: British National Formulary (available at: www.evidence.nhs.uk/formulary/bnf/current)

Background to opioid analgesics

Opioid drugs act in the central and peripheral nervous system. They produce their effects by activating opioid receptors, which are coupled with inhibitory G-proteins, located in the central nervous system, peripheral nervous system and peripheral tissues. This leads to the inhibition of voltage sensitive calcium channels and reduces adenylyl cyclase activity,⁸⁰ and results in a reduction of neuronal cell excitability that in turn reduces transmission of nociceptive impulses.

Opioids can be natural, synthetic or semi-synthetic. Natural opioids are those derived from the alkaloids found in opium, such as morphine, codeine and thebaine. Semi-synthetic opioids are derived from natural opioids, and include oxycodone (derived from thebaine), hydrocodone (derived from codeine) and dihydromorphine (derived from morphine). Synthetic opioids are synthesised from chemicals and molecules that do not come from the alkaloids found in opium but share the ability to bind to and activate opioid receptors. Examples of synthetic opioids include methadone, fentanyl and tramadol.⁸¹ Some opioids – including codeine – are prodrugs that exert their analgesic effect after metabolism.

Appendix 2 – Palliative care strategies in the UK

Wales

In Wales, *Together for Health – Delivering End of Life Care* was published in 2013 to set out the Welsh Government's expectations for how the NHS delivers end-of-life care.⁸² It identifies a range of priorities including detecting and identifying patients, and providing information to generalists on how to access support from specialist services, supporting training for primary care teams, improving communication skills and promoting multidisciplinary team meetings to discuss patients and targeting research.

England

The End of Life Care Strategy for England was first published in 2008, and highlighted the importance of a care pathway approach for commissioning and delivery of integrated care. In 2014, *Actions for End of Life Care 2014-16* was published. Whilst it doesn't have a specific focus on pain relief, it provides a framework for setting out broad commitments to end-of-life care.

Northern Ireland

Living Matters: Dying Matters was published by Northern Ireland's Department of Health, Social Services and Public Safety in 2010 and provides a strategy for adult palliative and end-of-life care.⁸³ It recommends that lead commissioners should be identified and that systems should be in place to capture population needs to better inform commissioners, including for non-cancer conditions. It highlights the importance of integrated care pathways, so that a patient's care is planned and seamless.

Scotland

In Scotland, *Living and Dying Well* was published in 2008 setting out the Scottish Government's action plan for palliative care. Building on *Living and Dying Well*, the *Strategic Framework for Action on Palliative and End of Life Care 2016-2021* was published by the Scottish government in December 2015.⁸⁴

Acknowledgements

Editorial board

Board of science chair	Professor Parveen Kumar
Policy director	Raj Jethwa
Head of public health and healthcare	Lena Levy
Head of science and public health	George Roycroft
Research and writing	Robert Wilson
	Thomas Andrews

Board of science

This report was prepared under the auspices of the BMA board of science, whose membership for 2016-17 was as follows:

Professor Pali Hungin	President
Dr Mark Porter	Council chair
Dr David Wrigley	Council deputy chair
Dr Andrew Dearden	Treasurer
Dr Anthea Mowat	Representative body chair
Professor Parveen Kumar	Board of science chair
Dr Paul Darragh	Board of science deputy chair
Dr JS Bamrah	
Professor Peter Dangerfield	
Dr Shreelata Datta	
Dr Kitty Mohan	
Mr Ram Moorthy	
Dr Melody Redman	
Professor Michael Rees (deputy member)	
Dr Penelope Toff	
Dr Ian Wilson	

Jacqueline Adams (BMA Patient liaison group representative)

Dr Iain Thomas Robert Kennedy (BMA public health medicine committee representative)

The Association is grateful for the help provided by the BMA committees and outside experts. We would particularly like to thank:

- Dr Beverly Collett OBE (Faculty of Pain Medicine)
- Professor Mike Bennett (Faculty of Pain Medicine)
- Professor Andrew Rice (Imperial College London)
- Professor Roger Knaggs (University of Nottingham)
- Dr Martin Johnson

References

- 1 British Medical Association (2016) *End-of-life care and physician-assisted dying: Volume 1 – Setting the scene*. London: British Medical Association
- 2 British Medical Association (2016) *End-of-life care and physician-assisted dying: Volume 2 – Public dialogue research*. London: British Medical Association
- 3 British Medical Association (2016) *End-of-life care and physician-assisted dying: Volume 3 – Reflections and recommendations*. London: British Medical Association
- 4 <http://www.ncpc.org.uk/news>
- 5 Murtagh FEM, Preston M & Higginson I (2004) Patterns of dying: palliative care for non-malignant disease. *Clinical Medicine* **4**: 39–44.
- 6 World Health Organization, WHO Definition of Palliative Care. Available at: www.who.int/cancer/palliative/definition/en
- 7 <https://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware>
- 8 Economist Intelligence Unit (2015) *Quality of Death Index 2015*. Available online at: www.economistinsights.com/healthcare/analysis/quality-death-index-2015
- 9 Zin CS, Chen LC & Knaggs RD (2014) Changes in trends and pattern of strong opioid prescribing in primary care. *European Journal of Pain* **18**(9): 1343-1351.
- 10 Higginson IJ & Wei G (2012) Opioid prescribing for cancer pain during the last 3 months of life: associated factors and 9-year trends in a nationwide United Kingdom cohort study. *Journal of Clinical Oncology* **30** (35): 4373-9
- 11 Deandrea S, Montanari M, Moja L et al (2008) Prevalence of undertreatment in cancer pain. A review of published literature. *Annals of Oncology* **19**(12): 1985-1991
- 12 Gao W, Gulliford M, Higginson IJ (2011) Prescription patterns of analgesics in the last 3 months of life: A retrospective analysis of 10202 lung cancer patients. *British Journal of Cancer* **104**(11): 1704-10.
- 13 Ziegler LE, Mulvey MR, Blenkinsopp A et al (2016) Opioid prescribing for cancer patients in the last year of life: a longitudinal population cohort study. *Pain* **157**(11):2445-2451.
- 14 Dixon J, King D, Matosevic T et al (2015) *Equality in the Provision of Palliative Care in the UK: Review of Evidence*. London: London School of Economic and Political Science.
- 15 The Neurological Alliance (2003) *Neuro numbers: A brief review of the numbers of people in the UK with a neurological condition*. London: The Neurological Alliance
- 16 Harrison N, Cavers D, Campbell C et al (2012) Are UK primary care teams formally identifying patients for palliative care before they die? *British Journal of General Practice* **62**(598) e344-e352.
- 17 World Health Organization. *WHO's cancer pain ladder for adults*. Available at: www.who.int/cancer/palliative/painladder/en/
- 18 van den Beuken-van Everdingen MHJ (2007) Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Annals of Oncology* **18**(9): 1437-1449.
- 19 NICE (2012) *Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults*. Available at: www.nice.org.uk/guidance/cg140
- 20 <http://www.palliativecareguidelines.scot.nhs.uk>
- 21 British National Formulary, *Prescribing in Palliative Care – Pain*. Available at: www.evidence.nhs.uk/formulary/bnf/current/guidance-on-prescribing/prescribing-in-palliative-care/pain

- 22 Maltoni M (2008) Opioids, pain, and fear. *Annals of Oncology* **19**(1): 5-7.
- 23 Oldenmenger WH, Sillevius Smitt PAE, van Dooren S et al (2009) A systematic review on barriers hindering adequate cancer pain management and interventions to reduce them: a critical appraisal. *European Journal of Cancer* **45**: 1370-1380.
- 24 Hayle C, Coventry P, Gomm S et al (2013) Understanding the experience of patients with chronic obstructive pulmonary disease who access specialist palliative care: A qualitative study. *Palliative Medicine* **27**(9): 861-868.
- 25 World Health Organization (2004) *The solid facts: palliative care*. www.euro.who.int/__data/assets/pdf_file/0003/98418/E82931.pdf
- 26 Coventry PA, Grande GE, Richards DA et al (2005) Prediction of appropriate timing of palliative care for older adults with non-malignant life threatening disease. **34**: 218-227.
- 27 Marie Curie (2015) *Triggers for palliative care: Improving access to care for people with diseases other than cancer*. Available online at: www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-full-report.pdf
- 28 British Medical Association Ethics Department (2012) *Medical Ethics Today: The BMA's Handbook of Ethics and Law* (3e). London: Wiley-Blackwell/BMJ Books.
- 29 George R & Regnard C (2007) Lethal opioids or dangerous prescribers? *Palliative Medicine* **21**: 77-80.
- 30 Sykes N & Thorns A (2003) The use of opioids and sedatives at the end of life. *The Lancet Oncology* **4**: 312-18.
- 31 Lopez-Saca JM, Guzman JL & Centero C (2013) A systematic review of the influence of opioids on advanced cancer patient survival. *Current opinion in supportive and palliative care* **7**: 431-437.
- 32 Fohr SA (1998) The Double Effect of Pain Medication: Separating Myth from Reality. *Journal of Palliative Medicine* **1**: 315-28.
- 33 Gardiner C, Gott M, Ingelton C et al (2012) Attitudes of Health Care Professionals to Opioid Prescribing in End-of-Life Care: A Qualitative Focus Group Study. *Journal of Pain and Symptom Management* **44**(2): 206-214.
- 34 Seale C (2009) End-of-life decisions in the UK involving medical practitioners *Palliative Medicine* **23**: 198-204.
- 35 Rurup ML, Borgsteede SD, van der Heide A et al (2009) Trends in the Use of Opioids at the End of Life and the Expected Effects on Hastening Death *Journal of Pain and Symptom Management* **37**(2): 144-155.
- 36 Johnson IS (2005) Assisted dying for the terminally ill. *The Lancet* **366**(9495): 1433-1434.
- 37 Breivik H, Cherny N, Collett B et al (2009) Cancer-related pain: a pan-European survey of prevalence, treatment, and patient attitudes. *Annals of Oncology* **20**(8): 1420-33.
- 38 Reid CM, Gooberman-Hill R & Hanks GW (2008) Opioid analgesics for cancer pain: symptom control for the living or comfort for the dying? A qualitative study to investigate the factors influencing the decision to accept morphine for pain caused by cancer. *Annals of Oncology* **19**(1): 44-48.
- 39 Parliamentary and Health Service Ombudsman (2015) *Dying without dignity*. Available online at: www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity/1
- 40 The Scottish Parliament (2015) *A report for the Scottish Parliament by Professor David Clark: International comparisons in palliative care provision: what can the indicators tell us?* Available online at: www.scottish.parliament.uk/S4_HealthandSportCommittee/Reports/HSS042015R09.pdf

- 41 Marie Curie (2015) *Triggers for Palliative Care: Implications for Wales*. Available online at: www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-wales-summary.pdf
- 42 Marie Curie (2015) *Triggers for Palliative Care: Implications for Northern Ireland*. Available online at: www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-northern-ireland-summary.pdf
- 43 Regulation and Quality Improvement Authority (2016) *Review of the Implementation of the Palliative and End of Life Care Strategy (March 2010)*. Belfast: The Regulation and Quality Improvement Authority
- 44 ComRes (2011) *Dying matters Death and Dying Survey*. Available online at: comres.co.uk/polls/dying-matters-death-and-dying-survey-3/
- 45 King's Fund (2005) *Palliative care: perspectives on caring for dying people in London*. Available online at: www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/palliative-care-perspectives-dying-people-jenni-burt-cathy-shipman-julia-addington-hall-patrick-white-kings-fund-1-march-2005.pdf
- 46 National End of Life Care intelligence Network. www.endoflifecare-intelligence.org.uk/home
- 47 Belfast Health and Social Care Trust. www.belfasttrust.hscni.net/1576.htm
- 48 Royal College of Physicians (2016) *End of life care audit – Dying in hospital: National report for England 2016*. London: Royal College of Physicians
- 49 Marie Curie (2014) *Difficult conversations with dying patients and their families*. London: Marie Curie
- 50 Gomes B, Higginson J, Calanzani N et al (2012) Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology* **23**(8): 2006-15.
- 51 National Survey of Bereaved People (2013) VOICES. Available at: www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people--voices-.html
- 52 Russell PB, Aveyard SC, Oxenham DR (2006) An assessment of methods used to evaluate the adequacy of cancer pain management. *Journal of Pain Symptom Management* **32**: 581–588.
- 53 National Council for Palliative Care (2012) *Commissioning guidance for Specialist Palliative Care*. Available online at: www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf
- 54 Bennett MI, Ziegler LE, Allsop M et al (2016) What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large UK city. *BMJ Open* **6**(12):e012576
- 55 Wilson E, Morbey K, Brown J et al (2015) Administering anticipatory medications in end-of-life care: A qualitative study of nursing practice in the community and in nursing homes. *Palliative Medicine* **29**(1): 60–70.
- 56 British Medical Association (2013) *Community pharmacy: A guide for general practitioners and practice staff*. London: British Medical Association
- 57 Ziegler L, Bennet M, Blenkinsopp A et al (2015) Non-medical prescribing in palliative care: A regional survey. *Palliative Medicine* **29**(2) 177–181
- 58 Royal College of Physicians (2016) *End of Life Care Audit – Dying in Hospital: National report for England 2016*. London: Royal College of Physicians.

- 59 Macmillan Cancer Support (2011) *Dying out of hours: 24/7 care at the end of life conference report*. Available online at: www.ncpc.org.uk/sites/default/files/DyingOutOfHours_Conference_Report.pdf
- 60 Healthcare Improvement Scotland (2014) *Scottish Palliative Care Guidelines: Out of Hours Handover*. Available online at: www.palliativecareguidelines.scot.nhs.uk/guidelines/end-of-life-care/out-of-hours-handover.aspx
- 61 Faculty of Pain Medicine (2015) *Core Standards for Pain Management Services*. London: Faculty of Pain Medicine
- 62 Care Quality Commission (2015) *Inspection framework: NHS acute hospitals. Core service: End of life care*. Care Quality Commission
- 63 Hughes-Hallet T, Craft A, Davies C et al (2011) *Palliative Care Funding Review*. Available online at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf
- 64 Collins J (20.05.15) All healthcare professionals must be trained in palliative care. *The Guardian*. Available online at: www.theguardian.com/society/2015/may/20/all-healthcare-professionals-must-have-training-in-care-for-terminal-illness
- 65 Magee C and Koffman J (2014) Out-of-hours palliative care: what are the educational needs and preferences of general practitioners? *BMJ Supportive and Palliative Care*.
- 66 <http://services.parliament.uk/bills/2015-16/accesstopalliativecare.html>
- 67 Ingleton C, Gardiner C, Seymour J et al (2013) Exploring education and training needs among the palliative care workforce. *BMJ Supportive and Palliative Care* **3**: 207–12.
- 68 Together for Short Lives (2013) *Basic symptom control in paediatric palliative care*. Bristol: Together for Short Lives
- 69 <https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730>
- 70 Welsh Institute for Health and Social Care (2015) *Palliative care for children and young people in Wales: Meeting future needs*. Pontypridd: Welsh Institute for Health and Social Care
- 71 NHS England (2015) *Developing a new approach to palliative care funding*. Available online at: www.england.nhs.uk/wp-content/uploads/2015/03/dev-new-approch-pallitiv-care-fund.pdf
- 72 http://www.togetherforshortlives.org.uk/news/9592_seriously_ill_children_face_a_postcode_lottery
- 73 Heslop P, Blair P, Fleming P et al (2013) *The Confidential Inquiry into premature deaths of people with learning disabilities*. Bristol: Norah Fry Research Centre. Available online at: www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf
- 74 Help the Hospices (2012) *Towards excellence in hospice care: Widening access to palliative care for people with learning disabilities*. Available online at: www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/hth_learning_disabilities_doc_singles_06_lr.pdf
- 75 Regnard C, Reynolds J, Watson B et al (2007) Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *Journal of Intellectual Disability Research* **51**(4): 277-92
- 76 Royal College of Nursing (2013) *Dignity in health care for people with learning disabilities*. London: Royal College of Nursing.
- 77 Mencap (2009) *Living and dying with dignity: The best practice guide to end-of-life care for people with a learning disability*. Available online at: www.mencap.org.uk/sites/default/files/documents/2009-04/best_practice_guide.pdf

- 78 National Institute for Health and Care Excellence (2015) *Care of dying adults in the last few days of life*. Available at: <https://www.nice.org.uk/guidance/NG31>
- 79 Royal College of Physicians, British Geriatrics Society and British Pain Society (2007) *The assessment of pain in older people: national guidelines* (concise guidance to good practice series, No 8). London: Royal College of Physicians.
- 80 Vacanti C, Segal S, Sikka P et al (2011) *Essential Clinical Anesthesia*. Cambridge: Cambridge University Press
- 81 Sinatra RS, Jahr JS & Watkins-Pitchford J (2010) *The Essence of Analgesia and Analgesics*. Cambridge: Cambridge University Press.
- 82 Welsh Government (2013) *Together for Health – Delivering End of Life Care*. Available online at: gov.wales/docs/dhss/publications/130416careen.pdf
- 83 Department of Health, Social Services and Public Safety (2010) *Living matters: dying matters*. Available online at: www.dhsspsni.gov.uk/8555_palliative_final.pdf
- 84 The Scottish Government (2015) *Strategic Framework for Action on Palliative and End of Life Care 2016-2021*. Edinburgh: The Scottish Government.

British Medical Association

BMA House, Tavistock Square, London WC1H 9JP
bma.org.uk

© British Medical Association, 2017
BMA 20170191