

# Key recommendations on end-of-life care

Throughout 2015 we undertook a major project seeking views from our members and the public on their experiences, views and perceptions on end-of-life care and some aspects of physician-assisted dying. We commissioned social research experts TNS BMRB to design and conduct a series of 21 dialogue events across the UK, hearing from more than 500 doctors and members of the public. We published the final report in three volumes:

- volume 1 – setting the scene
- volume 2 – public dialogue research
- volume 3 – reflections and recommendations.

All of the reports and more information about the project can be found at: [www.bma.org.uk/endoflifecare](http://www.bma.org.uk/endoflifecare).

This paper summarises some of the key recommendations from volume 3, divided into recommendations for government; for providers of education and training; for doctors; and for healthcare providers.

## Recommendations for governments

In speaking with doctors and members of the public across the UK, we heard many examples of excellent practice. It was clear, however, that this was not universal, and that there is significant variability in the type and quality of services provided, both within and between geographical areas, and also, sometimes, between conditions. To address this variability, there is a clear role for governments across the UK.

**In order to make the significant number of achievable changes that will lead to the fairer provision of services, national governments need to make end-of-life care a top priority and work with other organisations to develop a clear, funded plan of action.**

Our report joins those from many other organisations in highlighting the inconsistencies in end-of-life care and calling for action. Yet despite it being widely recognised that those inconsistencies exist, and that improvements in care are needed, change has not happened quickly enough. We are calling for end-of-life care to be prioritised by all governments across the UK, both in terms of planning and funding.



Our aspirations should be realistic about what can be achieved in the short to medium term. The current emphasis on patient choice in many government strategies is meaningless without an infrastructure within which that choice can be realistically met, and can add to the pressure on doctors, patients and families. At the same time, this should not limit our ambitions to improve: the information we have gathered indicates that there are many improvements that might be made without significant investment and which may, in fact, have a beneficial impact on current financial, and other, challenges.

**National governments should initiate and fund high-profile public information campaigns encouraging people to think about, and make known, their wishes regarding end-of-life care.**

It was clear from speaking to members of the public at the events that most people did not think or talk about death and dying, and found such conversations uncomfortable and relatively taboo. Very few had thought about what they wanted at the end of life, and fewer still had shared their views with those close to them. Speaking to doctors, it was clear that this tendency to avoid discussing death and dying can make advance care planning difficult, and make decision making for patients who lack capacity far more complicated.

Amongst the public, there was a lack of information about the practicalities of end-of-life care and what it entails and a lack of knowledge about the options available for anticipatory planning: only a very small minority were aware of options such as making advance decisions about treatment or appointing someone else to make decisions on their behalf. When asked, most of the public stated that the majority of the information they have about end-of-life care comes from the media, both from highly sanitised and unrealistic portrayals on TV dramas and from “horror stories” about over-stretched NHS services and poor quality care on the news.

There is a clear need for more, balanced, accurate information about end-of-life care to be made available, and for the public to be encouraged to think about and share their wishes regarding care at the end of life. This is why we are calling on governments to initiate and fund high-profile public information campaigns such as Dying Matters in England, and Good Life, Good Death, Good Grief in Scotland.

**There should be formal mechanisms for collecting data on end-of-life care throughout the UK that are published on a regular basis and systematically reviewed.**

Over recent years, considerable efforts have been made to learn from experience. England is the only nation to routinely collect and publish data on the views of the bereaved on the quality of end-of-life care received by their loved one. There are currently no equivalent systematic data collection systems about end-of-life care in place elsewhere.

Comprehensive data are crucial for identifying where things are working well and less well, and for driving improvements in those areas. We believe that (in addition to robust mechanisms to investigate and examine individual complaints) there should be formal mechanisms for collecting data on end-of-life care, with data published on a regular basis and with systematic review in order to identify trends and problems and to measure the improvements in end-of-life care that governments throughout the UK are seeking.

**Funding should be provided to ensure that sufficient, high-quality bereavement services – including specific services for children – are available and accessible consistently throughout the UK.**

When discussing their fears and concerns about end of life and dying, huge numbers of participants expressed concern about how their family members would cope with their death and what support would be available for them. This concern was particularly acute for those participants who were parents.

Some of those who had recent experience of bereavement sadly reported that whilst emotional support was provided to the family while the patient was dying, this ended quite abruptly after death. Although some members of the public were aware of counselling and bereavement services available, they often did not know how to access them and were not provided with this information. On a larger scale, there were sometimes problems with availability of services and the ability of those services to meet the demand. Specialist services for children were even more sparse and could be particularly difficult to access.

Providing good bereavement support not only benefits those who use it, but relieves the anxieties of those approaching the end of life in knowing that support is available. This is why we are calling on UK governments to ensure funding is provided so that sufficient, high-quality bereavement services – including specific services for children – are available and accessible consistently throughout the UK.

## Recommendations for providers of education and training

It was clear from speaking with doctors at the events that not all doctors feel confident in dealing with all aspects of end-of-life care. This is particularly true for the huge number of doctors for whom end-of-life care is not the sole focus of their work, but who will play a crucial role in caring for dying patients.

We recognise the current demands of training programmes for doctors. Dying, however, is the one thing that will happen at some point to every person. We believe that caring for patients at the end of life should be seen as a crucial element of training for all medical students and doctors, embedded at all stages of their careers.

### **Acceptance of the inevitability of death needs to be emphasised early in doctors' training and throughout their careers.**

A significant issue raised at most of the doctors' events was the importance of identifying when patients may be approaching the end of their life, so that care can be appropriately planned, and a concern about the reluctance of some doctors to recognise that a patient might be dying, associating the death of a patient as a "failure".

There is a key role for education and training in promoting a culture shift in terms of the way in which some doctors view death. This culture shift should be implemented at as early a stage as possible, ideally with medical students receiving early exposure to dying patients and understanding their role in providing a good death. This should also be reinforced throughout doctors' careers.

Linked with this is the importance of ensuring that doctors recognise and accept that pursuing or continuing treatment might not always be in their patients' best interests and that failing to recognise this can sometimes lead to the provision of unnecessary aggressive treatments or inappropriate hospital admissions. We have long advocated that for every medical intervention a judgement should be made about whether that intervention will be appropriate and proportionate in the sense of providing a net benefit to the individual patient, taking account of their past and present wishes and values. This, balanced with the importance of ensuring patients are not abandoned or denied treatment for relievable conditions or symptom relief, must be emphasised in training.

**Doctors should receive more ongoing training in communication and listening skills and, in particular, in responding to “unanswerable” and difficult questions in an open, transparent and sensitive way.**

Doctors at the events recognised that good communication was a crucial aspect of good end-of-life care, but were candid about the fact that this did not always happen. Although the reasons for this were varied, large numbers of doctors expressed the view that there was a lack of training in this area, and that the training there was left them ill-prepared for the difficult conversations they faced.

In order to ensure that open, honest and sensitive conversations between doctors and patients can take place, we are calling for more training in communication and listening skills. Within this, there should be a specific focus on how to respond to difficult questions and be confident in talking about those issues with family members, including where there are difficult or dysfunctional relationships. Particularly important will be ensuring doctors feel confident enough to initiate conversations about the end of life with patients to ensure that conversations are held early enough to allow plans to be put in place.

Improving communication skills cannot be achieved by greater education and training alone, and must be supported by employers allowing the time and space for difficult conversations to take place, and by encouraging the public to overcome discomfort and to discuss their wishes for the end of life with their doctors and those close to them. We make various recommendations to this effect in other parts of our report.

**Doctors of all grades should receive training in the basics of pain control and understand when they should involve senior colleagues or colleagues from different disciplines in treatment.**

Pain was a major concern for the public when thinking about the end of life. Many doctors expressed a desire for more training, both in managing physical pain and in identifying other forms of pain and distress. Given this central importance of pain management to the public’s perception of a good death, we believe it is essential that doctors of all grades receive training in the basics of pain control, including understanding when to involve senior or more specialist colleagues.

Whilst there was an understanding amongst doctors at the events that they could, and should, administer strong analgesics or sedatives when necessary to relieve suffering at the end of life, many were concerned about how this action might be interpreted should the patient die shortly after. Although most of the doctors present did not feel this affected their own prescribing, there was some anxiety about colleagues being too conservative in their prescribing as a result. There will be a crucial role for education and training to address those anxieties, emphasising that the under-treatment of pain can be just as serious as the over-treatment of pain.

**Training should emphasise specific issues associated with mental capacity which are particularly applicable to the end of life.**

Doctors at our events acknowledged the clear legal processes and guidance in place for assessing mental capacity. There were mixed views, however, as to how confident doctors felt in doing this in practice, and many felt that although training for assessing mental capacity had improved, it did not always address the complexities around mental capacity assessment which can affect patients at the end of life.

Education and training in mental capacity should cover, in more detail, issues around capacity being decision-specific, fluctuating capacity, and assessing capacity in patients who may have dementia or other cognitive impairments. Training should also include understanding how doctors can help maximise decision-making capabilities, so that patients can be involved as much as possible in decisions about their care.

**Doctors should be mindful of the potential for patients at the end of life to be vulnerable to depression and training should ensure that doctors are able to diagnose and manage depression in those patients nearing the end of life, distinguishing it from natural sadness.**

One of the issues discussed with doctors at the events was the identification and treatment of depression in patients approaching the end of life. Interestingly, this was rarely raised spontaneously, and many doctors had to be prompted to consider it.

Many doctors expressed the view that depression could be very difficult to identify in patients approaching the end of life, a time when people will be experiencing a natural grief. A crucial aspect of training will therefore be to ensure that doctors can distinguish between natural sadness at approaching death and clinical depression which could be addressed through specific therapy – whilst, at the same time, recognising the need for ongoing support for all patients as they come to terms with a terminal condition.

## Recommendations for doctors

Our project identified a number of potential areas of end-of-life care for improvement. The onus is not on doctors to achieve these changes singlehandedly; however, there are a number of opportunities for doctors to make changes to their practice around end-of-life care that could yield significant benefits for patients and their families.

**The importance to patients of being treated as a person should be kept at the heart of all provision of end-of-life care services.**

When members of the public were asked to describe what good end-of-life care would look like, they were unanimous in their view that central to any approach would be for them to be “treated as a person”. Being treated as a person covers a wide range of ideas, but at its heart is the idea of being treated as a distinct individual, with particular needs, wishes and goals – and not being seen as “a number” or “a patient with cancer”.

There may be a tension between being able to treat patients as individuals and the tendency towards risk-averse practice – as can be seen, for example, in difficulties associated with discharge planning, which can lead to unnecessarily long hospital stays for patients who may wish to be at home in spite of the risks this may involve. Whilst doctors cannot, and should not, ignore serious risks, there is a balance to be struck. They should ensure that compassionate and individualised care is not sacrificed as a result.

Care should always be seen as the hallmark of the doctor’s role – and this should be emphasised particularly as patients approach the end of life; reassuring patients that they will not be abandoned even if a decision is made that the patient’s prognosis cannot be improved. More fundamentally, all patients should be cared for with dignity, respect and compassion. Kindness and a human, personal touch was valued by all attendees at the events. Although it can often seem a low priority for already overstretched staff, it is crucial that doctors appreciate its importance and recognise that for each individual patient, there is only one chance to get it right.

**More needs to be done to identify those patients, particularly but not exclusively, frail older patients with multiple comorbidities, who are likely to be approaching the end of their lives, and for this to trigger a review of the goals of different medical interventions and of the patient’s medication.**

A key issue raised at the events was the importance of identifying when patients may be approaching the end of their lives so that specific consideration can be given to their needs, wishes, and preferences for end-of-life care and plans put in place to support them. Many doctors expressed concern about the high number of inappropriate and repeated hospital admissions for patients at the end of life who experienced a medical crisis and in whom individual treatment episodes were seen in isolation, with nobody taking an overall view of the patient's health status. As a result, many patients spent their last weeks and died in hospital when, with early identification and appropriate planning, they could have remained at their usual place of residence.

For individual doctors, there will be numerous opportunities to help to reduce this and to identify patients who may be approaching the end of life and use this as an opportunity to initiate an appropriate conversation about their wishes and preferences, or to review treatment plans.

**The welfare of family members, and the impact on them of death and dying, is a matter of significant concern to the public and those providing treatment need to be aware of this and seek to address these concerns wherever possible.**

A key finding from our work was that members of the public frequently identified the impact on loved ones as one of their top fears and concerns about end of life and dying – yet this was rarely identified as such by doctors. This is a significant finding from which we can learn to help improve end-of-life care.

Although, quite rightly, it is the doctor's professional obligation to focus principally on the needs of the patient, it should always be kept in mind that what happens to the patient will also affect the health and wellbeing of those around them, and vice versa. Recognising and responding to the needs and wellbeing of family members; sharing information and involving family members in discussions about care (with due respect for confidentiality and consent); and demonstrating to the patient that their family and loved ones' needs are being considered are all examples of things doctors can do to help reduce anxiety amongst dying patients.

**Doctors should be familiar with the range of counselling and support services available, particularly those specific to young children, and signpost them as appropriate to patients and their families. Recognising the role these services can play in helping patients at all stages, such information should not be considered only towards the very end of life.**

As noted above, the impact on families and loved ones was a key concern for the public, far more so than doctors expected. A significant part of this concern was how family members – and, for those who were parents, their children – would cope with their death and what support would be available to them.

Providing good emotional support therefore not only benefits those who use it, but also helps relieve the anxiety of those approaching the end of their lives. For this reason, it is important that doctors are familiar with the counselling and support services available (particularly those specific to young children) and be able to signpost them as appropriate to patients and their families.

**Doctors should be conscious of their own emotional wellbeing and make use of the support services that are available to them at an early stage and before their health is adversely affected.**

It is important for doctors to remember to practise what they preach with regards to emotional support. It became evident at our events that caring for dying patients can have a significant emotional impact on doctors, regardless of their seniority or specialty. Doctors should remember to look after their own mental health and emotional wellbeing as well as those of their patients. We would like to see more availability and use of support services for doctors.

## Recommendations for providers of healthcare services

The recommendations we make for doctors to improve end-of-life care cannot be achieved in a vacuum. In order for doctors to be able to provide the highest quality end-of-life care, they must be able to work within environments and systems which are conducive to that.

**Doctors must be backed up by support from colleagues, managers and systems, which includes ensuring that time is allowed to ensure individual patient needs can be met.**

All of the doctors we spoke to wanted to provide the highest quality end-of-life care to their patients. It was felt that one of the major barriers to achieving this was, however, a lack of time.

In order to ensure that treatment is not provided inappropriately, doctors must be given time and space to consider their patient's overall health status and healthcare needs, in addition to responding to particular medical episodes. Conveying information about terminal illness in an appropriate way, ensuring that information is understood, and managing those conversations sensitively also takes time, as does ensuring appropriate handovers and transfers to different teams or services.

In hospitals, managers should ensure that rotas and work patterns allow time for appropriate handovers and team discussions, and detailed conversations with patients and those close to them. Careful consideration will also need to be given to how to achieve a similar change in general practice.

**Provisions should be put in place to ensure that doctors can access specialist clinical and practical advice, whenever and wherever that need arises.**

The expectation for the existing workforce should be that all doctors in clinical care have the core competencies required to care for dying patients. They should not be expected to be capable of managing every single aspect of that care but should be able to identify when specialist advice is required, and to access it whenever that need arises.

Although there are initiatives in place across the country to ensure specialist palliative care advice is available (e.g. telephone and e-mail advice services), these are either not widely available, or not widely promoted. Providers should ensure that such support is available and that information about how to access it is disseminated to all those who may come into contact with patients towards the end of their life. Doctors who are unaware of the services available to them in their area should contact their local palliative care provider for advice.

**Those responsible for organising services should ensure that mechanisms are in place so that doctors and other members of the team who are caring for patients at the end of life have access to formal and informal support as and when they need it and are aware of the range of services available to them.**

Dealing with death and dying can have a significant emotional impact on doctors and other members of the care team – regardless of their seniority or specialist experience with dying patients.

Although most of the reports and strategies on end-of-life care refer to the emotional needs of the patients and their families, very little attention is given to the emotional needs of doctors, yet this is something that came through very clearly from the events. We want to see those responsible for organising healthcare services ensure that formal and informal mechanisms are available for doctors and other members of the care team to access emotional support and counselling as and when they need it, whether that is an experienced colleague with whom to talk through difficult or challenging cases, support from occupational health services, or more formal counselling and support services. We would also like to see the use of such support services expanded and normalised so that individuals are encouraged and supported to access them at an early stage before their health is adversely affected.

**Those developing and delivering end-of-life care services – in hospices, hospitals, and in the community – should aim to make those services as family-friendly as possible.**

One of the key findings from the events was that the welfare of family members, and the impact on them of death and dying, was of significant concern for the public – although this was rarely identified as such by doctors. This is something that those responsible for organising and providing services need to be aware of.

Caring for and supporting a loved one at the end of life can be incredibly challenging – but there are some simple steps that can be taken to make things easier. Flexibility in terms of visiting hours, providing information about places to stay close-by, easy access to refreshments, facilities for children such as somewhere to play, and free car-parking or reasonable charges, can all help to support family members. Ultimately, this not only helps family members but may also help reduce anxiety amongst dying patients.

**Systems need to be in place to ensure the appropriate and timely availability of medication and equipment for patients being cared for in the community.**

Many participants at the events expressed a preference for being cared for at home at the end of life. The reasons behind this are clear: people wish to be cared for and die in a place that is familiar, comfortable and where they can be surrounded by their family and those important to them. Very few participants expressed a view about being cared for at home unreservedly, however, and many acknowledged that there could be factors which limit this option.

The management of pain and access to essential medications, for example, were particular concerns for the public. Doctors and those with experience of caring for relatives in the community, expressed the view that pain was seen to be less well managed in community settings than in hospitals. If patients are to be properly cared for in the community, access to essential equipment and medications, whenever they are needed, must be better facilitated.

Many participants also expressed a concern about being a burden on their families and the adequacy of support from other services to alleviate this. A key part of resourcing care at home, therefore, will be the provision of nursing and trained care assistant staff to support carers. Those responsible for providing services in the community must make this a cornerstone of their local palliative and end-of-life care service plans

**Dying in hospital should not necessarily be seen as a failure. Steps should be taken to improve the experience of dying in hospital along the lines of the hospice model.**

Being cared for and dying in a hospital was the least well regarded option by the public. This was largely due to a perception of the hospital environment being clinical or institutional, as opposed to the comfort, familiarity and normality of being cared for at home and the flexible and personalised care associated with hospices.

As noted above, for many participants the appeal of dying at home was about comfort, familiarity, dignity, privacy, and being able to maintain as normal a life as possible. Crucially, they valued being able to have their families and loved ones around them. Provisions and flexibility to allow families to be with their relatives towards the end of life (even on a very practical level, such as information about accommodation near the hospital, refreshments, or car parking) will be an important step in achieving this. Those responsible for the running of a hospital should consider, therefore, how best to incorporate these elements in order to improve the experience of dying in hospital.

**Hospital prescribing systems need to ensure the appropriate and timely availability of medication, in the event of a sudden change in the patient's condition.**

Although problems with access to pain relief were primarily raised in relation to those being cared for in the community, access to drugs can also be a problem in hospitals where electronic prescribing means there is no drug cupboard on the ward and so more forward-planning is required for their access. Care is needed to ensure that systems, such as electronic prescribing, that are intended to improve efficiency do not have unintended negative consequences.

**Steps need to be taken to make discharge planning more effective, to identify the barriers to discharge and take steps to eradicate them.**

A common story from the events was the experiences of patients being admitted to hospital and then remaining there for considerable periods after their need for inpatient care had ended, because the necessary care package could not be put in place within a short period of time. In many cases delays were caused by difficulties in accessing the equipment, facilities or support needed. For patients who are at the end of their life this could mean the difference between spending their last days and dying in hospital or being in their own home.

Steps therefore need to be taken to make discharge planning more effective, to identify the barriers to discharge and take steps to eradicate them. Where delays in putting a package of care together are unavoidable, many patients would be happy to be discharged from hospital, despite what may be a less than ideal care package being in place. Where there are risks of discharge, but these are within an acceptable level, the situation should be explained to the patient, and/or the family, and their views should be sought and, where possible, acted upon.

**In order to ensure that deciding where to be cared for at the end of life is not just an illusory choice, there must be better coordination between different health and social services to enable the necessary support and practical arrangements to be put in place.**

It is increasingly rare that an individual's needs will be met by one service alone. Patients frequently need care from multiple services and they may require, or want, transfer between locations (home, hospital, hospice, care home etc.). It is in these circumstances that the provision of high-quality care can be particularly challenging.

It was clear from the events that where end-of-life care works well it is usually because all services involved in the care of the patient – including the hospital, GP, district nurses, voluntary groups, and social services – are coordinated by an identifiable and accountable individual. Whether it is through the creation of a new post, or the development of existing “main point of contact” or “named persons” systems, we believe that an end-of-life care coordination service should be available to each patient to ensure coordinated care and the sharing of relevant information.

One of the major barriers to the effective coordination of care is the lack of mechanisms for communicating information. In order to provide appropriate care in line with the patient’s preferences, it is crucial that every relevant health professional who has contact with the patient has all the relevant information they need – including diagnosis, prognosis, treatment plan, and the patient’s wishes. Doctors at the events shared many examples of good practice for information sharing - ranging from the use of patient-held notes to IT systems - but it was clear this was not universal. It will be vital for any future development of the healthcare system to ensure there is a mechanism for information to be shared across all relevant sectors.

**Patients approaching the end of life should be given information about the options open to them including alternatives to hospital care, such as local hospices, and realistic information about the support and services available to those who wish to be cared for at home.**

There was a clear information gap identified at the events by both members of the public and doctors in terms of the practical information provided to patients approaching the end of life and their families. Participants felt that (with due deference to individual preferences for the type and level of information) patients needed to be aware of, not only their diagnosis and prognosis and treatment options, but their options for place of care – including the alternatives for being cared for in a hospital, and the support available to them should they wish to be cared for at home.

Another issue that came up repeatedly in the events was the benefit of patients and their families having clear instructions about who to call if they needed help or advice – something which was seen as particularly crucial for those being cared for at home in preventing inappropriate hospital admissions in a crisis.

Patients and their families also need clear information about what is happening and what to expect. Many people have never been close to someone who is dying before, and the fear and uncertainty about what will happen can make the experience even more difficult, ultimately impacting on the family’s experience and recollection of the death.

**Thought should be given to the type of information and assistance patients and their families might need – including about legal and financial issues – and facilitate easy access to this including, where appropriate, allowing non-medical hospital staff to witness wills for those who wish to make them.**

Members of the public highlighted their need for very practical advice and information when facing the end of life and their uncertainty about how to access such information. This included information about the type of care, support, state benefits and services available to those with terminal illnesses; information about, and practical assistance with, making wills; and signposts to bereavement and support services available for families after death. They did not expect doctors to provide this information but saw a role for healthcare establishments in pulling together information from a range of sources as an information resource for patients and their families. This might be through a library-type resource, a stock of information leaflets, or a member of patient-support staff or volunteer who is able to direct the patient to relevant information or organisations.



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BMA 20160500