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# What's important to me.

*A Review of Choice in End of Life Care*

## **EXECUTIVE SUMMARY**



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Published by  
The Choice in End of Life Care  
Programme Board

February 2015

## About this review

The Choice in End of Life Care Programme Board was commissioned to provide advice to Government on improving the quality and experience of care for adults at the end of life, their carers and others who are important to them by expanding choice. Full details of the Review Board's terms of reference are available online.<sup>1</sup>

The Board membership was	
Claire Henry (Chair)	Chief Executive, National Council for Palliative Care
Helen Findlay	Person with experience of end of life care services
Ian Leech	Person with experience of end of life care services
Lynn Cawley	Person with experience of end of life care services
Sanjay Chadha	Person with experience of end of life care services
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Sharon Blackburn	Policy and Communications Director, National Care Forum
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Jane Allberry	Deputy Director, NHS Clinical Services, Department of Health
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Dr Peter Nightingale	End of Life Clinical Lead, Royal College of General Practitioners
Ruth Dixon	Association of Directors of Adult Social Services
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Anita Hayes	Programme Delivery Lead for End of Life Care, NHS Improving Quality

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As well as the organisations mentioned above, the Board would like to thank the following who have helped them in preparing this report and advice to Government:

Cicely Saunders Institute, University of Nottingham, Nuffield Trust, Together for Short Lives, Macmillan Cancer Support, and all the people and organisations who took the time to respond to the engagement exercise.

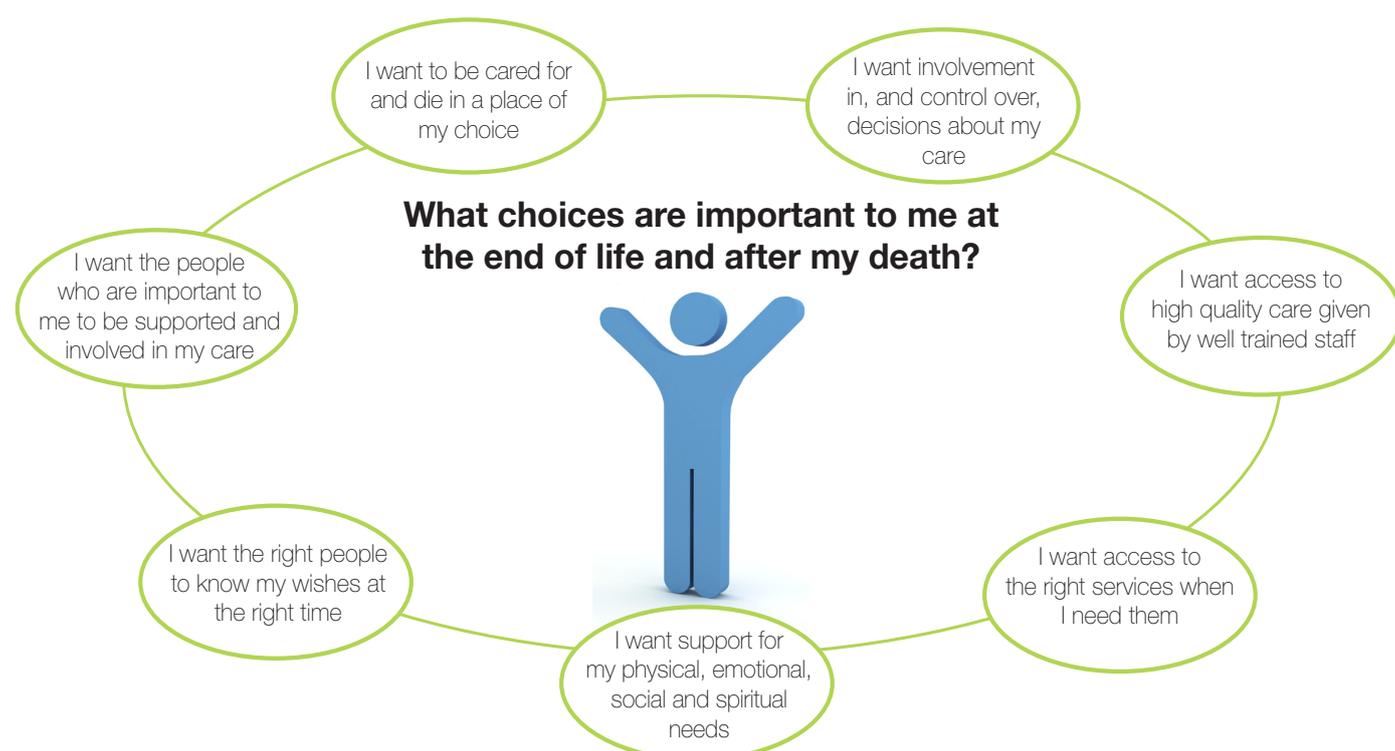
## Executive summary

End of life care<sup>2</sup> has made great strides forward in recent years, in particular following the publication of the End of Life Care Strategy in 2008.<sup>3</sup> However, we know that too many people still do not receive good quality care which meets their individual needs and wishes. For example, only just over half of respondents to the National Survey of Bereaved People (VOICES-SF) felt that their relative had died in a place of their choice.<sup>4</sup> At the same time the challenge of delivering consistently good experiences and outcomes for people at the end of their lives is growing. Each year, around 480,000 people die in England. This is predicted to increase to 550,000 by 2035.<sup>5</sup>

We were asked by the Government to consider how the quality and experience of care for adults at the end of life and those close to them could be improved by expanding choice.

This report identifies the issues people approaching the end of life are currently facing and offers a blueprint for how greater choice in end of life care can be achieved. Our advice is focused around a 'national choice offer' – a simple expression of what should be offered to each individual who needs end of life care.

In forming this advice to Government, we have engaged widely with the public, to ensure that individual experience is at the heart of our work and we are immensely grateful to everyone who came to us with their views and experiences. A number of key themes emerged from this engagement exercise. Many people told us that they wanted choice over their place of care and death; others told us that they wanted choices over other aspects of their care, such as pain control and involvement of family and those close to them.



We know that while many people are offered these choices now, many are not. We believe that asking everyone who is approaching the end of their lives a single question “what’s important to you?” can open the gateway to conversations that ensure people have choices and care that are focused around their needs.

Everyone who says they want to have these conversations should have them, regardless of where they live, their individual circumstances or their clinical condition. These conversations need to take place at the right time, as part of an honest and informed dialogue, throughout the individual’s care. To make this happen, we advise that there is a national choice offer for end of life care as follows:

**Each person who may be in need of end of life care is offered choices in their care focused on what is important to them. This offer should be:**

- **made as soon as is practicable after it is recognised that the person may die in the foreseeable future;**
- **based on honest conversations with health and care staff, which supports the person to make informed choices; and**
- **consistently reviewed through conversations with health and care staff.**

However, in our public engagement, many people said that as well as choices about their care, they wanted things like support for physical and emotional needs and access to the right care from well trained staff. We heard how many people did not receive good quality end of life care. This fits in with wider evidence that end of life care services are not consistently good across the country.

People told us that good end of life care needs to be provided to all people as a platform for a national choice offer. We know what good care is. It means that people get the right services, at the right time, in the right place. It means people’s preferences are heard, recorded, shared and acted upon. It means staff who can deliver care with expertise and compassion. It means people being informed about the treatment and care available to them, their condition, and how this might affect them over time. Only through consistent and comprehensive good care can choice be delivered and a national choice offer be meaningful.

To enable a national choice offer, we advise that a number of steps are taken to ensure good quality end of life care for all. Our advice provides a framework to enable both the better commissioning of high quality care and better delivery of these services by health and care organisations and their staff.

We need to support individuals in making their voices heard, and choices and preferences known, so we advise that:

- **each person who has consented to and wishes to specify choices and preferences in their end of life care has these recorded in their individual plan of care, with its details held on an Electronic Palliative Care Coordination System (EPaCCS) or equivalent system; and**
- **each person who wishes to express their end of life care choices and preferences in advance is offered a way to do this through access to their own medical records and plans of care and the ability to add and amend information on personal choices and preferences.**

We know that for many people approaching the end of their lives, support from family, carers and those important to them is vital in ensuring that they receive high quality care focused on their needs. We advise that:

- **carers for people at the end of life should be formally identified as such by the relevant services, that their eligible needs for support be met in line with the provisions of the Care Act 2014, and that support be provided for carers following bereavement; and**
- **family members, carers and/or those important to the individual should be involved, where possible, in discussions about care preferences where the dying person has said they should be.**

The services available for people approaching the end of life need to change to enable choices and preferences to be delivered. To achieve this, we advise that:

- **every local area should establish 24/7 end of life care for people being cared for outside hospital, in line with the NICE quality standard for end of life care, which supports people's choices and preferences;**
- **EPaCCS or equivalent system coverage is increased to 100% of localities to enable the recording and sharing of people's choices and preferences;**
- **EPaCCS or equivalent systems are fully accessible to view and update for all involved in the provision of end of life care services, in particular social care organisations, and that they align with the information on care plans offered to people with long term conditions and any social care assessments;**
- **each person in need of end of life care has a named responsible senior clinician who would have overall responsibility for their care and their preferences; and**
- **each person in need of end of life care is offered a care coordinator who would be their first point of contact in relation to their care and their preferences.**

To ensure that health and care services meet individuals' needs fully, health and care staff need to have the knowledge, support and skills to provide high quality care. To achieve this, we advise that:

- **Health Education England, Local Education and Training Boards and Skills for Care ensure that staff responsible for the delivery of end of life care have training focused on the key elements of their roles which enable choice such as early identification of needs, advance care planning, communications skills, shared decision making, the use of coordination systems (e.g. EPaCCS) and working in partnership with people and other organisations to design and deliver person-centred care; and**
- **there be greater joint working between palliative care specialists and other clinical staff, and between secondary care and primary care staff, to identify people who may need end of life care as early as possible.**

Many places already have many of these types of services and already offer and deliver good quality care and choice. However, we are also aware that ensuring that this happens everywhere will have financial implications, both spending more money and spending money in different parts of the health and social care system, at a time when funding is under significant pressure.

We have used a wide range of evidence to create a model of care which shows us what we spend on end of life care, and what it might cost if the system were changed to provide good quality personalised end of life care for all which delivers the choices that people would like to make.

This work has produced a number of costed scenarios for improvements in end of life care to deliver a national choice offer. The outcomes from that show that the only way to guarantee a level of care in line with all of the statements in the NICE Quality Standard for End of Life Care, for all locations, with everyone's choices and preferences met, would involve substantial investment - over £800million annually. We accept that in the current financial climate, at a time of great demands on NHS and social care services, this level of additional investment on an annual basis is unlikely.

However, our modelling suggests that a realistic, meaningful level of service improvement can be achieved through relatively modest investment which would make a significant difference to people's quality and experience of care at the end of life. We believe these improvements would make essential progress towards the implementation of a full national choice offer in end of life care. Therefore, we advise that:

- **an additional £130million is identified in the next spending review and invested in social care and NHS commissioned services to deliver a national choice offer in end of life care.**

It has been suggested that the NHS will require £8billion of extra funding, and that further

efficiency savings can also be found. We believe that the £130million that we recommend is spent on end of life care should be seen as a critical part of that £8billion and that this should be viewed in a wider context of decades of neglect of end of life care.

This is, however, only achievable if the people and organisations who deliver this care, in particular the NHS, change the way they work. It requires more care in community settings, with investment in these services coming from the savings flowing from reduced hospital-based care; it requires providers of hospital services to plan care proactively, beyond hospital, to avoid unnecessary admissions; it requires a change in attitudes and behaviour from all involved in the commissioning and delivery of care to make care truly person-centred; and it requires a skilled, capable and flexible workforce.

We know that, in some places, good quality care, focused around the individual's choices and preferences, already happens. At the same time, we recognise that not all NHS, social care and other services are ready to provide the sort of choice offer that we are recommending, and some of the changes that need to happen will take time.

However, we believe it is essential to set a specific date for the delivery of a national choice offer in end of life care and specific timescales for key service improvements, so that all people in all areas are able to benefit from this. We also believe the offer should be supported by inclusion in documents which outline people's rights in relation to NHS. We therefore advise that:

- **the national choice offer for end of life care be made by April 2020;**
- **this offer should be supported by a right in the NHS Constitution for everyone to be offered choice in end of life care and have these choices and preferences recorded and held in their individual plan of care;**
- **the offer should be reflected in the NHS Choice Framework, which provides information about rights to choice in the NHS, and publicised through the NHS Choices website; and**
- **our advice on 100% coverage for EPaCCS or equivalent systems be implemented by April 2018, and our advice on 24/7 care for people in community settings be implemented by the end of 2019.**

To support staff and organisations delivering care to build the services to ensure good quality care and enable choices by this date, the Government and other statutory organisations, including commissioners of health and social care services, need to create the right conditions. We advise that:

- **NHS England's new guidance for Clinical Commissioning Groups should make explicit reference to enabling preferences at the end of life;**

- **NHS England should also consider preferences at the end of life in its ongoing work on the NHS Standard Contract, new palliative care currencies, the service specification for specialist palliative care and updated toolkit for end of life care;**
- **Health and Wellbeing Boards consider enabling choice, better coordinated care and integrated models of end of life care in making strategic plans for their local areas;**
- **the potential for the use of personal budgets should be more fully explored and that provider organisations should consider how they can best support people to use personal budgets to enable their choices and preferences to be met;**
- **the existing incentives relating to end of life care in the Quality and Outcomes Framework should be reviewed to take into account people's preferences at the end of life, potentially with regard to the use of EPaCCS or equivalent systems;**
- **Health Education England, in planning for future workforce numbers, should:**
  - **work with commissioners and providers to agree both specialist and non-specialist palliative care workforce requirements, in acute and community settings, to deliver improvements in end of life care; and**
  - **take into account how breaking down organisational boundaries can allow staff working in acute settings to play a greater role in delivering care in community settings.**
- **the Government implement a clear policy to make access to social care for people at the end of life fast and free;**
- **health and social care commissioners include initiatives aimed at increasing community resilience and involvement in end of life care in their plans;**
- **the Dying Matters Coalition plays a key role in widening public understanding and supporting the development of choice and so should be encouraged, supported and sustained, as should initiatives aimed at building the confidence of health and care professionals on these issues;**
- **NHS and social care organisations work in closer partnership with the voluntary sector to support hospices in providing the services required to meet people's choices; and**
- **local areas who already have the systems and services in place to offer and deliver choice as outlined in the proposed national choice offer do this at the earliest opportunity, sharing their expertise with others through a central knowledge hub.**

We need to ensure through effective measurement that choice is being offered consistently and people are receiving the care that they have said they want. Therefore we advise that:

- **the work on individual-level outcome and experience measures for palliative care, being led by NHS England and Public Health England, should incorporate**

- **real time feedback and also measure the extent to which a person had been offered choice and whether their choices had been met. These measures should also provide meaningful data to monitor the impact of a national choice offer on health inequalities;**
- **indicators be developed for the NHS and Adult Social Care Outcomes Frameworks to hold the health and social care system to account for delivering choice and improving experience for all at the end of life; and**
- **the Care Quality Commission (CQC) inspection regime for acute and community trusts, primary care and adult social care (which includes hospices and care homes) uses the offer of choice to individuals in end of life care and the ability of organisations to facilitate and support coordinated care as signifiers of quality.**

Our work for this Review has been built on the wealth of evidence now available on end of life care, from academic research and specialist clinical advice, to work done by charities and statutory organisations. We believe that the insights provided by our engagement exercise have enriched this work and added valuable perspective and real-life experience. We do however recognise that there are some limitations in relation to our work, in particular on the costings of specific elements of good end of life care, such as staff training, named responsible clinicians and care coordinators. We advise that:

- **further work be done relating to these costs to support the implementation of the choice offer; and**
- **there be further research into palliative and end of life care, focusing on the priorities identified by the James Lind Alliance, which should provide a richer evidence base for key parts of this advice.**

We believe that a commitment to deliver choice in end of life care by April 2020 is essential. If we want to deliver high quality, personalised end of life care for all, we must ensure that everyone has the choice and access they need. People have very clear ideas about what is important to them at the end of life and what they need to support their care and their choices. We believe the advice we have set out here is a clear, sensible and straightforward way to make this happen.

## References

<sup>1</sup> Full details of the Review's terms of reference are available online at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/341515/Terms\\_of\\_reference\\_for\\_review.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/341515/Terms_of_reference_for_review.pdf).

<sup>2</sup> Historically there has been some confusion about the definition of the end of life and of palliative care as distinct from end of life care. This report uses those terms as they are defined in Annex G of the *One Chance to Get it Right* report, produced in June 2014 by the Leadership Alliance for the Care of Dying People. For the avoidance of doubt these definitions are as follows:

**End of life** - Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events. In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

**Palliative care** - The World Health Organisation has defined palliative care as follows: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

<sup>3</sup> Department of Health (2008). *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*. London: HMSO. [Online] Available from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/136431/End\\_of\\_life\\_strategy.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf).

<sup>4</sup> Office of National Statistics (2014). *National Survey of Bereaved People (VOICES-SF) by NHS area team (England) 2011-12*. London: ONS. [Online] Available from: <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/by-nhs-area-team--2011-2012/stb-national-survey-of-bereaved-people--voices-.html#tab-Preferences-and-choice-at-the-end-of-life>.

<sup>5</sup> Office of National Statistics, (2013). *2012-based National Population Projections (Released: 6 November 2013)*. London: ONS. [Online] Available from: <http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2012-based-projections/stb-2012-based-npp-principal-and-key-variants.html>.

