

# Time for Action



Why end of life care  
needs to improve, and  
what we need to do next

# Introduction

In the weeks surrounding the general election a number of important independent reports were published which together contained recommendations about why and how people's experience and quality of care at the end of life needs to be improved:

- *What's important to me: a Review of Choice in End of Life Care*, the report of the Choice in End of Life Care Programme Board commissioned by the last government ('Choice Review')
- The House of Commons Health (Select) Committee published a report on end of life care<sup>i</sup>
- *Dying without dignity. Investigations by the Parliamentary and Health Service Ombudsman (PHSO) into complaints about end of life care*

All these came after *One Chance to Get it Right* was published in 2014 by the Leadership Alliance for the Care of Dying People, following the independent review into the Liverpool Care Pathway led by Baroness Neuberger. This identified five priorities for the care of dying people.

Although much has been achieved since the first national End of Life Care Strategy was published in 2008, the scale and rate of change need now to be stepped up significantly if we are to ensure that everybody receives high-quality end of life care at the right time and in at the right place. There are still too many stories of people receiving inadequate care at the end of their lives<sup>ii</sup>. Staff surveys continue to show low levels of confidence and insufficient training in end of life care, particularly in relation to symptom control and communication<sup>iii</sup>. Well-documented inequities in access to palliative and end of life care, whether by diagnosis, age, gender, ethnicity, deprivation, or geography, have persisted for too long<sup>iv</sup> (also see page 3). Although a series of national documents have said that care of dying people is core business for the NHS<sup>v</sup>, the reality does not always reflect this.

**Collectively these reports have created a powerful case for an accelerated step change in the priority that is given to caring for people at the end of life.**

Whilst some of the recommendations the reports contain will require a response from the new government, many of them can be implemented straightaway, and indeed are already underway in some places. For example, we know that the majority of CCGs either have operational Electronic Palliative Care Co-ordination Systems or have work underway to achieve that<sup>vi</sup>. Many – perhaps the majority – of the findings and recommendations in these reports are not new. We know what needs to be done; the challenge now is to do more of it, faster.

# Have we heard this before?

## The issues we face are not new.

- For example, inequity by diagnosis has been a feature of palliative and end of life care for many years. NCPCC found the following quote from the Health Minister in **1998**, in its archives. Others might well be aware of much earlier, similar exhortations.

“The principles of palliative care, which are being taken for granted in voluntary and NHS Hospices, need to become integrated into the whole of our NHS practice. This needs to be achieved for *all those who face life threatening illnesses*” (actual italics), Baroness Jay of Paddington, Minister of State, Department of Health 1998<sup>vii</sup>

- In **2003** the then Chief Executive of the NHS, Sir Nigel Crisp, said: “*Better care of the dying should become a touchstone for success in modernising the NHS. This is one of the really big issues – we must make it happen.*”<sup>viii</sup>
- The House of Commons Health (Select) Committee held an earlier inquiry into palliative care<sup>ix</sup> in **2004**. Its findings included inequity of access by diagnosis, age, ethnicity and complexity

of need, as well as limited choice and problems with delayed discharge and staff training. Its recommendations included:

- “We believe that the introduction of electronic patient records in palliative care would be particularly beneficial to patients, given the need for so much support to patients out of normal working hours, and the need to involve a wide range of health professionals in care at the end of life”
- “We would urge the appropriate Royal Colleges to ensure that training in palliative care becomes part of continuing professional development, and to consider making such modules a mandatory requirement for revalidation”
- “If palliative care is to achieve improvements in the quality of the last months of life across the population it will need to operate in a much more equitable way. It will also need to be delivered more strategically and to find a way of overcoming the divide between health and social care”

**The purpose of this short report is to enable decision-makers at every level, including those responsible for commissioning and providing services and research, to understand the key findings of these reports as well as their recommendations about what is needed. It also includes some recommendations by the National Council for Palliative Care (NCPCC).**

This report is published in anticipation of the work of the Ambitions Partnership, a group of national organisations across the voluntary and statutory sectors that has come together to develop a new five-year vision and a fresh set of ambitions for end of life care over the coming parliament. Its vision will be published later in 2015 and will provide new momentum for change.

# Themes

The multiple recommendations in these reports are based on four key calls for change:

- 1. Leadership:** end of life care needs to be given much greater priority throughout the health and care system
- 2. More out-of-hospital care:** we need to develop well-coordinated community-based care that will keep more people out of hospital and get them discharged in a timely fashion in accordance with their preferences and clinical needs
- 3. Supporting the workforce:** the care people receive should always be compassionate, competent and confident
- 4. Eliminating unfairness and inequalities:** people's quality and access to end of life care should not depend on their age, diagnosis, where they live, or anything other than their needs and their preferences



## Leadership: End of life care needs to be given much greater priority throughout the health and care system

There is significant inconsistency in quality of care. For example, the Care Quality Commission reports that whilst 60% of hospitals it has inspected provide end of life care that is good or outstanding, 40% are inadequate or need improvement<sup>x</sup>. This level of variation – into which unfairness, inconsistency, and sheer bad care can also be read – is not acceptable in any area of care. This is not primarily about money but about priority, behaviour and culture change.

Reports calling for “more”, “better” or some other different type of leadership are familiar<sup>xi</sup>, and can too often be interpreted as “somebody else should do something”. The recommendations in these reports are more specific: the purpose of leadership required is to ensure that end of life care is seen as a core priority throughout every relevant organisation in the system.

The Health Committee referred to evidence that clear leadership on end of life care is lacking within Government and made recommendations for named and public accountability at every level:

- *“The Department of Health and NHS England should ensure that end of life care is prioritised and embedded in future planning at all levels. They should identify named individuals who will be responsible for ensuring that the new approach to end of life care, based on the Five Priorities, is delivered nationally.”*
- *“A senior named person in each NHS Trust and care provider should be given responsibility for monitoring how end of life care is being delivered within their organisation”*

The PHSO's report stressed that making end of life care a priority is a task for everyone working in the NHS: *“How we die is part of the core business of the NHS and a matter of concern to all”*. It recognised the leadership of the Ambitions Partnership in coming together to generate a new vision and ambitions and urged *“the whole of the NHS to find the collective will to make those ambitions a reality”*.

The need for this is not confined to the NHS. Research by NCPC and Hospice UK<sup>xii</sup> has found that only 43% of Health and Wellbeing

Boards (which are led by Local Authorities) made explicit reference to the end of life care needs of their populations in their Joint Health and Wellbeing Strategies (JHWS).

NCPC agrees with the Health Committee's recommendations that named individuals should have responsibility for end of life care in each relevant organisation and believes that should be included **explicitly in job descriptions**. It also recommends that every

organisation providing end of life care should **publish annually an account** of what their organisation is doing to improve people's quality and experience of care at the end of life, as part of their annual reporting.

NHS England's *Actions for End of Life Care: 2014-16*<sup>xiii</sup> will give local leaders more details about national priorities, to inform their local planning.



# 2

## More out-of-hospital care:

**We need to develop well-coordinated community-based care that will keep more people out of hospital and get them out more quickly (if that is their preference and appropriate for their clinical needs)**

Whilst hospital will continue to be an appropriate place for many people to be cared for and die, for many others it is not. Privacy, peace and dignity are often in short supply, and surveys consistently show that the majority of us would prefer the familiarity of home. Enabling more people to die outside hospital was one of the core objectives of the 2008 End of Life Care Strategy. Thanks to the efforts of many organisations and people, progress is being made and less than half of us now die in hospital (49% in 2013<sup>xiv</sup>). However there is still a long way to go if everybody's preferences and wishes are to be met. Care outside hospital needs to be well-planned and co-ordinated if avoidable unplanned admissions are to be reduced.

The reports made a number of important recommendations that would help to improve out of hospital care. These included:

- **Care planning.** Everyone in need of end of life care should have a care plan that meets their needs and preferences. The PHSO's report highlighted care planning as a weakness.
- **Co-ordination.** People's plans, wishes, and preferences for their care need be recorded and accessed by all the services involved in their care. This requires local

electronic information-sharing systems (for example Electronic Palliative Care Coordination Systems - EPaCCS) to be made available across the country. These have not yet been rolled out everywhere. Where they have been, relevant voluntary sector organisations, for example hospices, have not always been included

- **Care co-ordinators.** The Choice Review recommended that each person in need of end of life care should be offered a care-coordinator to be their first point of contact in relation to their care and preferences.
- **Each local area should establish 24/7 community-based end of life care.** This should include access to essential services including pain relief. Barriers to social care should be removed, to enable people to stay out of hospital or be discharged more quickly if they are in hospital. NCPC recommends that commissioners and providers should stop thinking in terms of "out of hours" services and to start designing services that meet people's needs "at any time of day and night", as recommended by NICE<sup>xv</sup>.

NCPC will publish a further report on keeping and getting people out of hospital later in 2015.

# 3

## Supporting the workforce: The care people receive should always be competent, compassionate and confident

The PHSO identified a number of issues in which the health and care workforce needs support to ensure it is always competent, compassionate and confident. In particular she highlighted the need to:

- Recognise when people are dying
- Make sure symptoms are properly controlled
- Improve communication and care planning
- Bring an end to delays in diagnosis and referral

The Choice Review recommended that staff responsible for the delivery of end of life care have training focused on the key elements of their role, including needs identification, communication, shared decision making and advance care planning.

The Health Committee also highlighted the preparedness of the workforce; five of its 25 recommendations were explicitly about workforce issues. These included competence and training, as well as recruitment to ensure that there are sufficient staff in community settings.

Workforce issues need to be seen in context: after decades of decline, numbers of people dying each year in England are predicted to increase from about 480,000 to about 550,000 by 2035<sup>xvi</sup>. With those overall numbers, every percentage point change in place of care and place of death means about 5,000 people being cared for and dying in a different setting to what is currently happening. This requires a significant shift in service design and resources, including staffing.

Responsibility for addressing skills and capacity gaps in the workforce lies at a number of levels. Health Education England, Local Education & Training Boards and Skills for Care all received explicit recommendations about workforce planning and training curricula, in each of the three reports.

There are also important issues for providers. The PHSO found that “*some clinicians need to be more confident with established good practice, such as the skilled use of morphine and other opiates*”. This again is not a new issue. Dying in pain is a significant public fear<sup>xvii</sup>. There is no good reason why clinicians should not be more confident in the use of morphine and titration, as well as symptom control more generally. There has been too little recent progress. For example, the annual VOICES surveys of bereaved people show no significant change in the numbers of people who died at home who were reported always to have had access to pain relief, over the four years between 2011 and 2014<sup>xviii</sup>. Clear, honest and effective communication is also an essential skill. Ensuring end of life skills are up to date and releasing staff for training need to be a priority for management, governance, and regulation.

NCPC will publish a more detailed report on workforce issues in 2016.

# 4

## Eliminating unfairness and inequalities: We need to get end of life care right for everyone, regardless of the circumstances of their lives, where they live or what their diagnosis is

Dying does not make equals of us all. End of life care is still riddled with inequity and inequalities. Age, gender, deprivation, marital status and geography also have an impact on people's access to and quality of care, as well as diagnosis. This has been evidenced in many reports over the years<sup>xix</sup>, including NCP's annual Minimum Data Set for Specialist Palliative Care (MDS). For instance, whilst the MDS has revealed some improvement in access to specialist palliative care by people with conditions other than cancer, it is still overwhelmingly dominated by people who have cancer. Depending on service setting 64-85% of people seen in specialist palliative care have cancer<sup>xx</sup>, although cancer accounts for only about 29% of deaths<sup>xxi</sup>.

To tackle this commissioners and providers need to take a **“whole community” approach to service planning**. The Health Committee recommended that commissioners should explicitly set out how they will provide specialist palliative care services for people from all backgrounds and with all diagnoses. The Choice Review Board found that: *“A ‘national choice offer’, made to everyone regardless of where they live, their individual circumstances or their clinical condition, should be the mechanism for ensuring that good end of life care happens everywhere.”*

This will require close attention to be paid when drafting commissioning and service specifications, to ensure that services work as well for people with conditions other than cancer as they do for people with cancer. People's quality and access to care should not depend on their age, diagnosis, where they live, or anything other than their needs and their preferences. Commissioners and providers should not be content with replicating existing services but should be proactively seeking to innovate and develop models that will enable everyone to access end of life care when they need it. Again this is happening in some places, but not everywhere.

There is also a need to **prioritise evidence and intelligence** more seriously than has been done to date. This means more robust and comprehensive data collection at individual level, and greater investment in research at the end of life. Currently just 10p in every £100 spent on health research is spent on end of life care<sup>xxii</sup>.





# The government's agenda for end of life care

The new government prioritised end of life care in its manifesto, explicitly setting this in the context of whole-system integration:

*“Too many people spend their last days in hospital when they would prefer to die closer to home; we will support commissioners to combine better health and social care services for the terminally ill so that more people are able to die in a place of their choice. We will continue to integrate the health and social care systems, joining-up services between homes, clinics and hospitals, including through piloting new approaches like the pooling of around £6 billion of health and social care funding in Greater Manchester and the £5.3 billion Better Care Fund”.*

This evidence of commitment is very welcome, although the detail needs now to be fleshed out. Pooled budgets and integrated services could bring significant improvements to end of life care. However, if this is to be achieved, end of life care needs to be written explicitly into the frameworks that govern integration work. This is not currently happening. For example, the Memorandum of Understanding for the Greater Manchester Health and Social Care Devolution<sup>xxiii</sup> stops short of end of life care, referring instead to improving health and wellbeing “from early age to the elderly”. The Five Year Forward View, published by NHS England in 2014, did not include any substantive ambitions for end of life care.

Integration also needs to be seen as including the voluntary sector as an equal partner, not something solely or principally for the statutory sector. This is particularly true in end of life care, where the voluntary sector provides the majority of specialist palliative care<sup>xxiv</sup>. There is anecdotal evidence that many hospices have not been involved in local Better Care Fund plans and internal analysis by NCPC of Better

Care Fund plans indicates that only a small minority explicitly mentioned end of life care.

The Choice Review Board found that despite the cradle to grave ambitions of the NHS, there had been “decades of neglect of end of life care” and recommended that an additional £130 million be identified in the 2015 Comprehensive Spending Review and invested in social care and NHS services to deliver a national choice offer. The government needs to address that recommendation explicitly, as well as all the recommendations in these three reports, when setting out its plans to improve end of life care over the next five years.

End of life care should be seen as a litmus test for all government and system-led initiatives to improve health and care. A seven-day NHS must ensure that people at the end of life receive the care they need round the clock, regardless of their setting. Similarly the Secretary of State for Health has spoken of his desire to make the NHS the safest service in the world. The PHSO’s report made it clear that too many people are not safe at the end of life, when they are at their most vulnerable. Initiatives to improve safety must be seen to work for the benefit of people at the end of life.

It is also essential to recognise that dying, death, and bereavement are not purely health and social care issues, but affect the whole of people’s lives. This means that we need a much wider and richer public debate about how we support each other at times of crisis and loss. NCPC’s pathfinder project for the Dying Well Community Charter<sup>xxv</sup> (supported by Public Health England) is a contribution to this, as is the work of the Dying Matters coalition, led by NCPC (supported by NHS Improving Quality). It also means that we need to review the whole-life impact of dying, death, and bereavement.

Areas which need detailed focus include: the extent to which the **benefits system** supports people who are going through dying, death and bereavement (their own or that of somebody close to them); **compassionate employment** policies, including bereavement leave and support; **coroner rules** surrounding home deaths; personal, social, health and economic education in **schools**; **wills and intestacy**, particularly as family structures and relationships become more complex and fluid.

The Dying Matters coalition and its members have already campaigned to raise awareness on some of these issues, but

further Government action is now required. Just as the Prime Minister's Dementia Challenge has raised the profile of dementia, so the Government needs now, as part of its leadership on end of life care, to consider the way that government and statutory organisations deal with and support people through dying, death and bereavement. NCPC asks the government to consider the example of the Irish Taoiseach, and appoint an independent person to review<sup>xxvi</sup> the way in which all government departments and branches of the state deal with end of life issues, and in particular those outside health and social care.

## What next?

2015 must be a momentous year for end of life care in England. The findings of three significant independent reports, taken together with the forthcoming publication of New Ambitions by the Ambitions Partnership, and a new government committed to improving end of life care, present an extraordinary opportunity for a step-change. All policy-makers, commissioners, providers, local leaders and health and care staff, as well as society at large, have a part to play. The time for action is now.



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<sup>i</sup>HC 805 2015

<sup>ii</sup>Well-publicised stories of poor care include, most recently, those documented in the PHSO report.

<sup>iii</sup>Examples include: Royal College of Nursing survey 2014 [www.rcn.org.uk/newsevents/news/article/uk/dying\\_in\\_the\\_uk\\_nurses\\_raise\\_profound\\_concerns](http://www.rcn.org.uk/newsevents/news/article/uk/dying_in_the_uk_nurses_raise_profound_concerns); Improving end-of-life care: professional development for physicians (2012) Royal College of Physicians

<sup>iv</sup>Examples of reports on inequalities include those published by the National End of Life Care Intelligence Network (most recently *What we know now 2014*); NCPC's annual Minimum Data Set for Specialist Palliative Care (MDS); *Equity in the Provision of Palliative Care in the UK: Review of Evidence* (2015) Personal Social Services Research Unit, London School of Economics and Political Science

<sup>v</sup>Examples include: The End of Life Care Strategy (2008); A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015 (page 6); One chance to get it right (2014) Leadership Alliance for the Care of Dying People (page 75)

<sup>vi</sup>Electronic Palliative Care Co-ordination Systems (EPaCCS) in England: Survey of clinical commissioning groups (2013) by the National End of Life Care Intelligence Network (2014) Public Health England & NHS Improving Quality

<sup>vii</sup>Writing in the foreword to "Reaching out: specialist palliative care for adults with non-malignant diseases" (1998) The National Council for Hospice & Specialist Palliative Care services (now NCPC) and the Scottish Partnership Agency for Palliative and Cancer Care

<sup>viii</sup>2020 Vision (NCPC) 2005

<sup>ix</sup>HC 454-1 (2004)

<sup>x</sup>Presentation by Sir Mike Richards, Chief Inspector of Hospital, November 2014

<sup>xi</sup>For example "End-of-life-care" King's Fund (2010)

<sup>xii</sup>Most recently: *Mapping England's Health and Wellbeing Boards' vision for dying people* (2014)

<sup>xiii</sup>*Actions for End of Life Care: 2014-16* NHS England (2014)

<sup>xiv</sup>ONS (2013) Deaths in England and Wales

<sup>xv</sup>NICE Quality Standard, End of Life care (2011)

<sup>xvi</sup>*What's important to me*

<sup>xvii</sup>Polling for Dying Matters by ComRes in 2011 found that 83% of respondents reported as being very or fairly scared of dying in pain.

<sup>xviii</sup>ONS National Survey of Bereaved People (VOICES) 2014

<sup>xix</sup>See iv above and Box 1

<sup>xx</sup>National Survey of Patient Activity Data for Specialist Palliative Care Services. MDS full national report 2013-14 (2015)

<sup>xxi</sup>ONS Deaths registered in England & Wales (2013)

<sup>xxii</sup>"The crisis facing terminally ill people and their families" NCPC and others (2014)

<sup>xxiii</sup>[www.agma.gov.uk/cms\\_media/files/mou.pdf](http://www.agma.gov.uk/cms_media/files/mou.pdf)

<sup>xiv</sup>For example approximately 60% of people seen by specialist palliative care community services that respond to NCPC's national Minimum Data Set collection are seen by independently-managed organisations

<sup>xxv</sup>[www.ncpc.org.uk/communitycharter](http://www.ncpc.org.uk/communitycharter)

<sup>xxvi</sup>[www.ehospace.com/ArticleView/tabid/10686/ArticleId/15324/language/en-GB/Default.aspx](http://www.ehospace.com/ArticleView/tabid/10686/ArticleId/15324/language/en-GB/Default.aspx)

## About NCPC

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and

people with personal experience to improve end of life care for all.

NCPC leads the Dying Matters coalition which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

NCPC is a registered charity number 1005671 and a company limited by guarantee number 2644430.

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