The end of life care strategy: New ambitions

A report based on a national conference held in November 2013
About the 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.

www.ncpc.org.uk

NCPC leads the Dying Matters coalition, which aims to change public attitudes and behaviours around dying, death and bereavement.

www.dyingmatters.org
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Why this report? Why now?

2013 was the halfway point of the 10-year 2008 End of Life Care Strategy ("the Strategy"). To mark that, the National Council for Palliative Care (NCPC) held a conference “Refreshing the strategy. The next five years for end of life care: what do we need to do?”.

This was in the context of a decision announced by NHS England in the summer of 2013, to “refresh” the strategy at its 5-year point. The “refresh” also needed to take account of the health and care reforms that had been implemented from April 2013, together with recommendations from the reports on both the Liverpool Care Pathway and Mid Staffordshire Foundation Trust, and the failures in care that occurred.

Since then it has emerged that NHS England will not now be refreshing existing national strategy documents, but instead will be publishing new sets of ambitions and actions.

This report includes reflections from the conference day, but is not a verbatim report, as it also includes additional recommendations and thoughts about what next in end of life care. It is intended as an initial contribution and will be followed by further publications during 2014-15.

“We’re at a turning point. End of life care is on the agenda. We have a chance, as never before, to get it right” —Tony Bonser, Chair of People in Partnership Group, NCPC and Dying Matters
Recommendations for action

The recommendations that follow are based on the discussions that took place at the “Refreshing the Strategy” conference. NCPC will develop these recommendations in further publications during the course of 2014-15.

1. The national end of life care strategy 2008 was a 10-year strategy for the whole system that has been demonstrably successful. Any refresh of the existing strategy or new set of ambitions and actions for end of life care must have the same level of authority and ambition, to command support across the reformed health and care system. End of life care needs a strong credible vision together with priorities for action that local decision-makers can align their plans around. Otherwise there is a danger that momentum and recent achievements will be lost.

2. Any refreshed strategy or new ambitions and actions for end of life care must be explicitly linked to other national priorities such as care for people with dementia, and plans for vulnerable older people.

3. There must be a “proper National Conversation about dying”, as proposed in the “More Care, Less Pathway” report following the Neuberger review into the Liverpool Care Pathway. By this we mean that everyone, including members of the public, health and social care staff and the media are given opportunities to meaningfully take part in discussions about dying to raise awareness and understanding of this important part of life that we will all experience, and help ensure that we make people’s care and experience as good as it can be.

4. Death in the Usual Place of Residence is a useful proxy measure, but does not give insight into the quality and experience of care. Priority must be given to developing a means to measure individual-level outcomes for end of life care that enable us to tell whether people had a good experience and if the care they received was of benefit.

5. To improve people’s experience of coordinated care, any local plans submitted to the Better Care Fund should include specific proposals for end of life care.

6. Good end of life care must become everybody’s experience. This means that any “national choice offer” on end of life care must be universal, for everyone, regardless of their age, gender, geographical location and setting, disability, diagnosis, or long-term condition/s, sexual orientation, socio-economic status, or ethnicity.
Context for the conference: Where have we come from and where have we got to?

The Strategy was published in 2008, the 60th anniversary of the NHS, and came with the recognition that in those 60 years of a cradle-to-grave service, insufficient attention had been given to end of life care. A great deal of work went into its development over the 2 years between the announcement that it would be developed and its final publication. There was an advisory board, six working groups and widespread stakeholder consultation. End of life care had also been identified as one of 8 key priorities for improvement in Lord Darzi’s NHS Next Stage review that took place during the same period.

The Strategy had a broad vision, and explicitly took a “whole systems” approach to drive improvement. Funding was attached to it in its first two years, following the then government’s manifesto commitment “to double the investment” in palliative care. It was ambitious for end of life care, arguing that the way we care for dying people says something fundamental about our values as a society, as well as the health and care system:

“How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.”

As a result of the energy and resource that went into its development, implementation of the Strategy was strongly supported, generating considerable momentum and buy-in. And, whilst there is still much to do to ensure that everybody gets end of life care that is as good as it can be, the work inspired by the Strategy has made a significant difference. This includes changes in people’s place of care and death, raised public awareness and behaviour change through the work of the Dying Matters coalition, workforce development and organisational guidance, much of which was driven by the National End of Life Care Programme until it was disbanded as part of the wider NHS reforms in March 2013, and improved data and evidence, much of it delivered through the work of the National End of Life Care Intelligence Network now part of Public Health England. A great deal has been done by many people and organisations at national, regional and local level, and all involved should be commended.
Place of death

One of the core insights underpinning the Strategy was that whilst the number of deaths in England and Wales had been falling steadily year on year for decades, it was predicted that they would start to rise from about 500,000 each year and would reach about 590,000 by 2030. Medical advances and other factors had enabled us to postpone death, but not to cancel it altogether. This was taken together with a long-term decline in the proportion of people dying at home, which was about 18% in the middle of the last decade. Yet opinion surveys were consistently showing that most people said they would prefer to die at home. There was a disconnect between where most people said they wanted to die, and the reality. Existing end of life care provision was not consistently good enough, and would certainly be inadequate in face of the rising demographic pressures.

As a result, in the years since the Strategy was published, a great deal of attention has been paid to place of death as an outcome measure. There have been some nuanced developments: focus now includes the place of care before death as well; and Deaths in the Usual Place of Residence (DiUPR), which includes people who died in care homes as well as in their own home, has been introduced as a key performance indicator.

By this measure, the Strategy has made demonstrable progress. The long-term trends in place of death have not just flattened out but been reversed. 2012 was the first year in many years that the proportion of people in England and Wales dying in hospital dropped below 50% (49.5%). 22% of people died at home, 20% in care homes, and 6% in hospices. The difficulty in reversing trends that had become entrenched over decades should not be underestimated.

With about 500,000 people dying in England and Wales each year, each percentage point change means 5,000 people being cared for and dying in a different setting. However, whilst there has been real improvement in place of death, there is scope for much more. For example there is evidence that people who have access to community based nursing or specialist palliative care services, or who are included on a local care co-ordination system, are more likely to die at home than the rest of the population. 22% of people die in their own homes, but 46% who receive care in the community die at home.

Where electronic palliative care coordination systems (EPaCCS) have been introduced, there is evidence that this is enabling better identification of people at the end of life, facilitating conversations about choices at end of life, and recording and sharing of these preferences. This also supports people to receive care and die in the place of their choice.
Quality of care

As the Strategy has matured, so has understanding of how best to measure good outcomes in end of life care. Whilst DiUPR has been useful as a driver of change and service redesign, there is increasing dissatisfaction with it as a proxy measure for quality. It does not give any insight into the deceased person’s quality and experience of care.

At the same time there has been a series of reports and scandals about unacceptable care in both the NHS and the care system, the most well-known of which is the Francis report into the Mid Staffordshire NHS Foundation Trust. These are not confined to end of life care, but many of them have included people at the end of life. The Neuberger review into the Liverpool Care Pathway (LCP), “More Care, Less Pathway”, made it clear that, whilst many people who died “on the LCP” received good care, that there were also far too many cases of people who had been treated poorly, both those at the end of their lives and their families.

The national bereavement survey (VOICES) reports on what bereaved people say about care of the deceased in the last 3 months also highlight problems. For example the second survey reported 48% of people were not always treated with dignity and respect in hospital by nurses, and this was also reported as true for 41% of people by hospital doctors, albeit that this was a slight improvement on the year before. The report also showed that 19% of people who died at home always had access to pain relief. If more people are to be cared for outside hospital, and to die in community settings, access to pain and symptom control at any time of day and night is essential.

The NICE Quality Standard on end of life care for adults (2011) contains 16 statements about what are the hallmarks of delivering good care in a locality, including access to pain relief and medications. However, NICE Quality Standards are not mandatory for commissioners.
Future priority and momentum

It is very much to be welcomed that the Government has identified end of life care in the Mandate to NHS England for 2014-15 as a priority area “where the Government is expecting particular progress to be made”.

However, notwithstanding that, there is a real risk that the momentum behind the Strategy will be dissipated. Any new set of ambitions and actions for end of life care, whether refreshing or superseding the current Strategy, will need to command the same level of credibility and respect and to create a vision for end of life care around which local decision-makers can align commissioning outcomes.

It is also important that end of life care is seen as part of a whole-life course approach to improving people’s experience of care, and explicitly linked to new initiatives in other priority areas of care, such as older people and dementia.

Any new ambitions and actions for end of life care will need to be informed by the work set in train by the Leadership Alliance for Care of Dying People, convened following the Neuberger review. The Leadership Alliance report is due to be published in the summer of 2014.

Themes for the future

Dr Bee Wee told the conference that the plans to refresh the Strategy would be based on the following over-arching themes:

- Having a shared understanding and purpose for end of life care
- Patients and carers feeling supported and able to cope
- Professionals feeling supported and able to learn and to care
- Addressing inequity and variations in practice
- Developing systems that support efficient and effective palliative and end of life care
The key challenges identified at the conference

In the presentations and debates at the conference, the following key challenges emerged.

1. Personalised care must be commissioned on the basis of local needs

Care and support must be truly personalised and coordinated, around the needs of the person, and their family. The issue of choice and control – a fundamental tenet of personalised social care – is simply not working for some people at the end of life. The commitment has been made in theory by both the NHS, and local authorities, yet the NCPC regularly hears from people for whom personalised, integrated care and support is simply not happening.

Action must be taken so that everyone’s needs are met

Whilst everyone is an individual with differing needs, there is also a commonality to many people’s needs (access to health care, specialist palliative care, physiotherapy, speech and language therapy, social care, including aids and equipment, for example) meaning that there can no longer be an excuse as to why services are not in place to meet these needs.

The new NHS structures, and the anticipated reforms to social care proposed by the Care Bill, mean that health and social care services should be commissioned and provided locally, from a range of providers. The theory is that this should mean that adequate local solutions can be found to ensure pain relief and symptom control is available 24 hours a day, 7 days a week, as care would be commissioned based on people’s needs (based on geography and population). However the reality is very different.

Any assessment of people’s needs must be done promptly, and services put in place promptly to meet those needs – whoever provides and funds those services. The so-called “postcode lottery” shouldn’t be used as an excuse as to why service provision is poor or patchy, but as a way to commission seamless care locally in ways that are appropriate to local demography and geography.
The artificial barrier between health and social care is often used as an excuse as to why services can’t meet people’s needs, or why services aren’t available in a local area; but this barrier is only in place because of the way that social care and health are funded, and a way to work around this must be found so that people at the end of life don’t experience unnecessary delays. Many people experience delays of difficulties claiming continuing healthcare funding, one of the ways in which the health service might pay.

The £3.8bn Better Care Fund\(^8\) (formerly the Integration Transformation Fund) was announced by Government in the June 2013 spending round, to ensure a transformation in integrated health and social care. Those who make decisions about its funding awards must ensure they fund bids where end of life care is included, making sure there is parity between health and social care. To improve people’s experience of coordinated care, any local plans submitted to the Better Care Fund should include specific proposals for end of life care.

It is increasingly clear that people at the end of life and those close to them want someone to coordinate their care and support. Plans have been announced for a named GP for the over 75s,\(^9\) and there have been calls for a social worker to be a care co-ordinator at end of life,\(^10\) but there is no national offer around a coordinator for everyone approaching the end of life. There is no consensus about what the function of this care coordinator would be, nor what competencies they would need, but they would need to command recognition and respect across and within all settings and sectors (including, acute, primary and social care) in order to ensure good care and support is put in place in a timely way.

The financial pressures upon local councils and health authorities are clear, but there are also costs to not getting end of life care right, for example increased emergency admissions, and lengthier hospital stays; but also for people who are forced to stop working and claim state benefits, either because of the time needed to care, or co-ordinate care; or following a “bad” death of someone they loved, or if they have an employer who can’t afford to pay sick leave or can’t offer reduced hours or workload.

The conference opened with a lengthy session in which delegates heard first-hand from people with personal experience about their needs. The voice of people approaching the end of life and those close to them needs now not just to be heard at conferences and in reports, but acted on. Effective listening must lead to change.
2. Challenges for the care and support sector – including end of life and palliative care services

End of life care is complex. People at the end of life are cared for, and supported, in a variety of settings: acute hospitals, hospices, in their own home, by their GP practice, care homes, and home care. This care and support is commissioned and provided by a range of services – from the statutory, voluntary and private sectors. NHS England, local authorities and Public Health England, must work with CCGs and Health and Wellbeing boards (HWBs) to commission and ensure provision of care. All these organisations have an important role to ensure good end of life care. Greater clarity and understanding is required about their respective roles and accountabilities.

A risk is that if end of life care and bereavement support is not included in a local strategy, for example a Joint Strategic Needs Assessment, that adequate services will not be commissioned. NCPC’s 2012 research showed that (of those HWBs whose strategy was publically available), fewer than half of those boards had explicitly considered dying people; and 30 strategies failed to mention people approaching the end of life either directly or indirectly.11

“It’s a challenge to be heard in a complex sector”
Dr Terry Lynch, GP, and Clinical Lead for End of Life Care, Horsham and Mid-Sussex CCG

“We must support commissioners to move away from acute care”
Dr Jane Collins, Chief Executive, Marie Curie Cancer Care
There are also challenges for the care sector in meeting the needs of those people who are self-funders, and the new market-shaping duties in the Care Bill may give this group better service.

> “Community care does work... There are savings. But the organising of care is an overhead”

Dr Jane Collins

Indeed, has the NHS grasped the concept of a good death? Does it still see death as a failure?

> “I’ve heard people – professionals – say ‘people at risk of dying’. We’re all at risk of dying.”

Tony Bonser

> “A good death is a good outcome, not a failure”

Dr Justin Varney, Consultant in Public Health Medicine (Adults and Older People), Health and Wellbeing, Public Health England

Demographic and social change also presents challenges for hospices and specialist palliative care, which need to reflect on how their services can help support older frail people living with a variety of long term conditions. The Commission into the Future of Hospice Care\(^\text{12}\) recommended that the sector needs to prepare for significant change to palliative and end of life care; strengthen the understanding of the contribution of hospice care; establish hospice care as a solution to the future challenges in palliative and end of life care; strengthen the connection between hospices and their local health and social care systems and local communities; and strengthen the leadership of hospice care. These recommendations challenge the hospice care sector to make sure they are reaching out to all who need palliative and end of life care.
Funding for palliative care is complex, with some services being commissioned and paid for through the NHS and many others being supported through voluntary sector fundraising. Following the palliative care funding review work is being done to evaluate the data collected from pilot collection sites, to inform the development of currency and tariffs. However, it is still not clear what services will be included within a new funding mechanism. This requires policy decisions to be made by the Department of Health.

The intention is to provide a funding model that will provide a robust and consistent financial offer for palliative care. However concerns were expressed that the case for specialist palliative care is not always made, leading to this care being under-commissioned; and that where palliative care is provided by generalists, they must be properly trained and supported in end of life care.

“Most people don’t need a doctor or a nurse, they need people who care and who can listen”
– Dr Justin Varney
Greater priority needs to be given to data and intelligence

Improving data and intelligence in end of life care was a key part of the Strategy. A great deal of work has gone on since 2008, much of it led by the National End of Life Care Intelligence Network. As a result we know much more than we used to about where people die, and the conditions they die from. Much less is known about the person’s quality and experience of care, and whether the things that were important to them were identified and met. Other important gaps include access to primary care and social care data.

Consistency of collection was identified as an issue, both in social care and specialist palliative care. Particularly in the voluntary sector, for understandable reasons, priority has been given to investing in frontline services not back-office functions. However, in the new environment, services providing end of life care need to be able to evidence the value of the services they provide in terms of measuring the benefits to people in a cost-effective way.

Currently much of the data collected in relation to end of life care is about inputs and outputs. A vital challenge is the lack of a universally recognised outcome measure, to enable an individual’s quality and experience of care to be assessed and understood. This would make it possible to tell whether people had a good experience and benchmark services and localities accordingly. It could have a transformative effect on the planning and commissioning of future services, as well as on people’s quality of care.

“If providers don’t like place of death, what alternative would they prefer their work to be measured by?”
– Simon Chapman, Director of Public and Parliamentary Engagement, NCPC and Dying Matters
4. Care must be universal, for everyone who needs it

Care must work well for everyone at the end of life, no matter their age, gender, disability, diagnosis, or long-term condition/s, sexual orientation, deprivation, ethnicity, where they live, or in whatever setting they need care.

**Care must be available wherever, whenever, whoever needs it**

“We didn’t fit into boxes”
Lynn Cawley, Carer, and Member, NCPC People in Partnership Group. Lynn’s son had learning disabilities, as well as other complex needs

“We are not good at referring non-cancer to palliative care”
Dr Jane Collins

“People with dementia don’t get the palliative care they need”
Eve Richardson, Chief Executive, NCPC and Dying Matters

NCPC’s annual MDS collection\textsuperscript{13} shows that access to specialist palliative care is dominated by those with a diagnosis of cancer, or that includes a cancer diagnosis. In 2012-13 only 20% of new patients referred to specialist palliative care services had a diagnosis other than cancer. According to the ONS’s Mortality Statistics: Deaths Registered in England and Wales (Series DR), 2012, cancer accounts for around 29% of all deaths.\textsuperscript{14}
With the rise in the numbers of older people, more must be planned so that this group’s needs are met.

“We must accelerate the work because of demographic changes... We must run faster! ... Can you access specialist palliative care at home or in the community if you’re old? Yet this group will increase.”

Dr Jane Collins

The government is considering the feasibility of introducing a national choice offer to support people who want to die at home. Any such national offer must be universal, applying to everyone, regardless of who they are, what conditions they have, or where they live.

“Can the sector support a national choice offer?”

Dr Jane Collins
5. Better conversations about death and dying; and involvement

As Justin Varney said at the conference “GPs are taught to recognise a set of problems, but we don’t train people well enough about how to talk about death”. Part of Dying Matters’ work has been to train GPs in confidence-building and communication skills around how to have better conversations about death and dying, with demonstrable improvements in practice; only 39% of doctors received pre-registration training in communicating with people approaching the end of their life.¹⁵

We must keep the “balance between hope and reality” [Tony Bonser] in having these conversations; hope for as long as possible, but not shying away from the reality. There may be a conflict between some of the narrative around long-term conditions, where the focus is on living well, for as long as possible. Whilst this is important for many at the point of diagnosis, and in coming to terms with living with a disability or long-term condition, there is a flip side:

“People with long-term conditions, from diagnosis, there needs to be a conversation and awareness that the person needs to be thinking of end of life issues... At all levels – consultants and nurses – they were protecting me from the conversation as ‘you don’t need to worry about it for years’. This was misguided loyalty.”

Sanjay Chadha, Co-Founder Asian Multiple Sclerosis (MS) Support Group and Member, NCPC People in Partnership Group
6. Compassionate communities

Death has been over medicalised, but part of the challenge now is to see death as a life event, not a medical one; which means we all need to change how we think and prepare for death. The work of the Dying Matters coalition, set up as part of the Strategy, has been to change knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make ‘living and dying well’ the norm.

Dying Matters has made good progress since it was launched. Over 30,000 members from a variety of fields have joined, including pensioner and retirement groups, financial services, lawyers, funeral directors and schools as well as health and social care. There is evidence that people are becoming more open to discussing death dying and bereavement and to planning ahead\(^{16}\). However there is more to be done to ensure that death becomes everyone’s business and that people are supported in every aspect of life. For example, recent research showed that one third of people who had cared for a bereaved person had not felt supported by their employers\(^ {17}\). Dying Matters is campaigning for employers of all sizes to put in place compassionate policies which cover support for carers and bereavement leave.

“What do compassionate, resilient communities of care look like in the future? What can we do now to foster and define them, and develop their capacity & capability to live and die well? … A new social and community model is needed”

Eve Richardson

“Employers will have a role to play in supporting bereaved people, because of the nature of the ageing workforce”

Dr Justin Varney

There is a cost to bereavement, the high cost of funerals, as well as the implications in areas that may not have been thought of, e.g. the high proportion of young offenders, whose history included bereavement but who had received no support for it. “Tell Us Once”, the government service for telling (most) government departments once about a death (or birth),\(^ {18}\) is an initiative that “needs to be mainstreamed” [Dr Justin Varney]
Finally, one of the key recommendations of the Neuberger review was that “there needs to be a proper National Conversation about dying”. NCPC firmly agrees with this. We would take a national conversation to mean that everyone, including members of the public, health and social care staff and the media are given opportunities to meaningfully take part in discussions about dying to raise awareness and understanding of this important part of life that we will all experience, and help ensure that we make people’s care and experience as good as possible. This national conversation is essential, not only to help raise awareness and drive behaviour change, but also to ensure that end of life care becomes a priority for decision-makers at every level, nationally, regionally, and locally. In the new world, we need a new people movement to mobilise and agitate to ensure that end of life care in this country is as good as it can be.

“Dying Matters can help with the national conversation”
– Eve Richardson
Next steps

Initial recommendations generated by the conference are published at the front of this report. NCPC will develop these during the coming months, and will publish further contributions. In particular, we are considering the potential relationships between current and proposed initiatives in end of life care, including the government’s ideas for a “national choice offer”, the possibility of ending the means-test for social care for people at the end of life, local electronic coordination systems (EPaCCS), and the palliative care funding mechanism.
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- Dawn Chaplin, Head Nurse Patient Experience/Clinical Dean for Nursing, Heart of England NHS Foundation Trust
- Simon Chapman, Director of Public and Parliamentary Engagement, NCPC and Dying Matters
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