THE
**NATIONAL
COUNCIL** FOR
**PALLIATIVE
CARE**

Dying
Matters

'Let's talk
about it

Marie Curie
Cancer Care

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10 Questions to ensure good end of life care in your area

Contents

As Chair of the All-Party Parliamentary Group on Hospice and Palliative Care, I have been privileged to meet and hear about the personal stories of some extraordinary people who are working to ensure that everybody gets excellent end of life care. Access to services and quality of care is still unacceptably variable across the country. It often strikes me that at the end of life people can sometimes experience the very best, but also the very worst, that our health and care system has to offer. We all need to work together to change that.

End of life care affects all of us. We all die and the majority of us will experience the deaths of people we love a number of times before we die ourselves. The end of life is not a condition; it is an inevitable part of life. How we care for dying people was rightly described in the End of Life Care Strategy (2008) as "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."

With the new reforms to the NHS coming into effect in April 2013, we now need to make sure that end of life care is seen as a core priority for decision-makers at every level. Whoever we are, we have an opportunity to campaign for change. To do so effectively, we need to know what to ask, and who to ask it of. I commend this booklet which sets out clearly and simply the information we need to hold local decision-makers to account.

Although this booklet is for everybody, I hope that my parliamentary colleagues will also find it useful as they work to ensure their constituents get the care that they need. In England, on average, 4,250 people will die in each constituency during the lifetime of this Parliament. Thousands more will be bereaved as a result. We only have one chance to get it right for them and their families; there are no dress rehearsals for dying.

Fabian Hamilton MP, March 2013

Introduction

Almost 600,000 people in the UK die each year. 452,864 people died in England alone, in 2011. Their deaths directly affect many more people: those who cared for them, their families, friends and work colleagues, and others as well. In a recent public survey 54% of those asked said that they had been bereaved at least once in the last 5 years[1].

It is therefore essential to ensure that as the Government's reforms of Health and Social Care in England are implemented they are made to work for the benefit of people approaching the end of life and people caring for them, so that their quality and experience of care is improved.

This requires local action. Under the reforms there is a whole framework of new organisations and people all of whom can help improve end of life care. But they have a great deal on their plates, so it's important that they make end of life care one of their top priorities. The most effective way to influence them is by local people, with an interest in end of life care, challenging them and holding them to account. This publication is intended to help you, the reader, do just that.

This document focuses on health and social care in England. Whether you are somebody who wants to champion end of life care in your area, an MP or Councillor wanting to influence or scrutinise local decision-makers, or a commissioner or service provider trying to make the case for change and build local partnerships, this publication is intended to help you ask the right questions of the right people. We hope that you find this useful, and would welcome any feedback you have.

Please let us know how you get on using this publication by emailing us at policy@ncpc.org.uk

We will be producing similar documents for Wales, Northern Ireland and Scotland in due course.

What do we mean by "the end of life"?

The "surprise question" is often used to help identify people who might be approaching the end of life: "Would you be surprised if this person died in the next 12 months?" If the answer is no, it is a good time to offer to have conversations about their end of life and to start to plan their care.

So, in this document, people are 'approaching the end of life' if they are likely to die within the next 12 months. This definition is used by many national organisations. It includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions

- general frailty and coexisting conditions that mean they are expected to die within 12 months

- existing conditions if they are at risk of dying from a sudden acute crisis in their condition

- life-threatening acute conditions caused by sudden catastrophic events.

It should, however, also be recognised that many people can benefit from end of life and palliative care before the last 12 months of their life. For example, it is particularly important that people with dementia and other conditions which affect capacity are given the opportunity to plan ahead long before the last year of life.

Where we refer to people "at the end of life" we mean people who are imminently dying and might be in the last few hours or days of life.

Who do we mean by "carers"?

We mean people who provide unpaid support to a family member or friend – they are a crucial, but too often overlooked, part of end of life care.

QUESTION 1
Where are local people dying, and where are they being cared for before they die?

Why is this important?

Polls consistently show that the majority of people (about 60-70%) would choose to die at home, with hospices being the next most popular setting. Many fewer would prefer to die in hospital or care homes. However the reality is that over half of us still die in hospital. Although hospital will be the right place for some people, for many it will not be what they wanted, and will not bring peace, privacy or familiar surroundings.

One of the chief aims of the national End of Life Care Strategy (2008) was to enable more people to be cared for and die in their place of choice. There had been a long decline over many decades in the numbers of people who were dying at home, with increasing numbers of deaths occuring in hospital. However these trends have now been reversed. When the strategy was published about 58% died in hospital and 18% at home. In 2011, 51% died in hospital, 21.8% at home and 19.4% in care homes.

Although this is excellent news, there is still a long way to go before everybody is being cared for and dying in the place they want to be, as well as considerable local variation.

What else to ask?

Although people's preferred setting is important, we still need to ensure they get the support and care they need. Some people are more likely than others to spend the end of their lives and die in care homes. This includes women aged over 75, and people with dementia and some other (but not all) neurological conditions, for example Parkinson's. It is important to make sure that there are good relationships and links between care homes and other local services, so that people living in care homes do not become a "hidden population". This is a responsibility for everybody involved in end of life care, not just care homes.

• Ask GPs and condition-specific services how often they visit people living in local care homes.

• Ask all local services, e.g. hospitals, primary and community care, hospices and care homes, how well they work together and how easy they find it to contact and receive support from each other.

Find out more

• The National End of Life Care Intelligence Network has published local population profiles containing data about people's age, gender, place and cause of death, as well as social care information, so you can find out what's happening in your area
www.endoflifecare-intelligence.org.uk

• The Marie Curie End of Life Care Atlas also provides information about care provision in different localities
www.mariecurie.org.uk/atlas

• The Marie Curie report Death and Dying: Understanding the data
www.mariecurie.org.uk

QUESTION 2
What are people saying about the quality of care they and their loved ones have received locally?

Why is this important?

We need to make sure not only that people can be cared for and die in the place that they want to be, but also that wherever they are, they receive high-quality well-coordinated care that meets their needs and preferences.

The NHS Outcomes Framework for 2013-14 measures improvements in end of life care by using the VOICES survey[2] of bereaved people to ask about the deceased person's quality and experience of care in the last 3 months of their life. The VOICES survey, which will be carried out annually, shows how local areas compare with the rest of the country, benchmarking each area against 11 indicators, including dignity, access to pain relief, coordination of services, place of care and involvement of carers.

Information from the VOICES survey needs to be read in conjunction with data about place of care and death. For example, although there is a national drive to support more people to be cared for at home, only 17% of bereaved people reported that where people had died at home their pain had been relieved "completely, all of the time". If people are to die at home they need access to pain and symptom control at any time of day and night (see further question 4). People also need emotional and practical support, for example what to do when somebody dies and who will come and take away equipment afterwards.

What else to ask?

• What else is being done to find out what local people think about their quality and experience of end of life care? In addition to the VOICES survey, which is carried out nationally and which is sent to people who registered deaths, individual commissioners and services should be thinking of ways to ask people approaching the end of life directly about the quality of their end of life care.

• What steps are being taken to address any local areas of concern raised by the VOICES survey?

Find out more

• The report of the first annual VOICES survey can be found at www.dh.gov.uk

The second annual report will be published during 2013

QUESTION 3
What local systems are in place to ensure that people who might be approaching the end of their lives have been identified and plans about their care can be coordinated?

Why is this important?

Good communication, care planning and coordination are essential if people's needs and preferences for their end of life care are to be met. It is therefore really important for local services to try to identify as many people who might be approaching the end of life as possible. This gives the opportunity to discuss and plan ahead with their care team and loved ones. The "surprise question" is helpful in identifying people (see page 5).

It is pointless to identify people who might be in the last 12 months of life without then taking some action, in terms of making plans and recording preferences and ensuring that local services can access information about them. People at the end of life frequently come into contact with a wide variety of teams and organisations. Their plans need to be recorded and their care needs to be coordinated so that all local services, including for example ambulance trusts, know what is supposed to happen. Locality Registers (also known as Electronic Palliative Care Co-ordination Systems, or "EPaCCS") are being set up across the country to enable this to happen. It is important to avoid jargon when describing these to people, so for example in London the EPaCCS is called "Coordinate my Care". Evidence suggests that people on an EPaCCS are more likely to be cared for and die in their preferred place (see question 2).

What else to ask?

- If there is a local coordination system in place:

  o How many people who died locally in the last year had been on the system?

  o How many of the people on the system have conditions other than cancer? Historically, palliative care has been much better accessed by people with cancer than other conditions, for example heart failure or dementia.

  o What happens when somebody is added to the system? Is their name simply put on a list or does this trigger discussion, planning and coordination?

- If there isn't a system in place – what plans are there to set one up?

Find out more

- About 1% of people die each year; that equates to about 20 people on an average GP list. The "Find Your 1%" campaign has been set up to help GPs identify people who might be approaching the end of life so that plans can be made with them about their care www.dyingmatters.org/gp

- Information about EPaCCS www.endoflifecare.nhs.uk

QUESTION 4
What services are available locally "at any time of day and night" to enable people to be cared for in the place that they want to be?

Why is this important?

If people are to be cared for outside hospital there are some services that they and their carers will need to be able to access at any time of day and night. Failure to ensure these are available may mean that people have inappropriate, unplanned emergency admissions. These can be alarming and frightening for those concerned as well as unnecessary and expensive.

In its 2011 Quality Standard for End of Life Care, NICE identified 16 markers of high-quality end of life care services. It contains a powerful challenge, recommending that 4 of those should be available to people approaching the end of life "at any time of day and night":

• Their physical and psychological needs should be met, including access to medicines and equipment

• Consistent co-ordinated care across all services

• Urgent care, in the event of a crisis

• Specialist palliative care

Other community-based services can help people stay out of hospital. Recent research by the Nuffield Trust has demonstrated that access to home-based nursing and also to social care can help people remain at home and avoid hospital admissions. Hospitals also need to ensure they can provide round the clock care, with sufficient staff and continuity of care.

N.B. NCPC actively discourages the language of "out of hours services", which is completely provider-centric. The needs of people approaching the end of life and their families arise round the clock and are not confined to other people's "normal" working hours of 9-5 Monday-Friday. The term 24/7 is commonly used instead.

What else to ask?

• What other services beyond those referred to above are available either at any time of day and night or on a sufficient basis to help people stay in their preferred place of care?

• If a service lacks the resources to provide 24/7 care, ask how it works with other providers locally, across all settings, to ensure services are available at any time of day and night?

Find out more

• The NICE Quality Standard on End of Life Care www.nice.org.uk

• Reports from the Nuffield Trust Patterns of Care at the End of Life project:

1. Understanding patterns of health and social care at the end of life

2. The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life
www.nuffieldtrust.org.uk

QUESTION 5
What support is available locally for carers of people approaching the end of life, including into bereavement?

Why is this important?

Numbers of people dying each year are predicted to start rising from about 2015, and more of them want and will need to be cared for and die in community-based settings. If this is to happen, a great deal of care will need to be provided by informal and unpaid carers, usually family and friends. Caring for somebody approaching the end of life can have a significant impact, including physical, emotional and financial.

Although both the End of Life Care Strategy (2008) and the Carers Strategy (2009) identified the importance of supporting carers for people approaching the end of life, neither considered how this could be done in any detail. However, NICE has recommended that families and carers of people approaching the end of life are offered both comprehensive holistic assessment and support. NICE also recommended that bereavement support be offered to all those who have been closely affected by a death. However, access to bereavement services is very patchy.

Carers for people approaching the end of life consistently tell us about the importance of access to information about what services and support are available locally, as well as the need for people to help them understand and navigate their way through the system(s). Carers should also be seen as experts in the care of the person approaching the end of life and an integral part of the team. This applies in all settings.

What else to ask?

• When a person is identified as approaching the end of life, what attempts are made to identify and assess the needs of their family and informal carers?

• Do the person approaching the end of life and their carers receive a holistic needs assessment to identify what information and support they need?

• What organisations operate locally that can provide practical support and advice to carers, including into bereavement?

• Ask local employers how they support people in their workforce who might be caring for somebody approaching the end of life or who has been bereaved recently.

Find out more

• Resources can be found at www.ncpc.org.uk/carers

• The NICE Quality Standard on End of Life Care www.nice.org.uk

• New Dying Matters support service mapping website www.help.dyingmatters.org

• See note on page 5 on who do we mean by "carers"

QUESTION 6
What is being done to ensure that local services are genuinely available and accessible to everybody in the local community?

Why is this important?

We all die and unless we die very suddenly, we will need care at the end of our lives. However, access to end of life care is patchy. It has been estimated that 92,000 people die each year without getting the palliative care that they needed[3]. Reasons for the variation include diagnosis, age, geography, ethnicity and deprivation. For example, people with cancer are disproportionately likely to access specialist palliative care[4], and people aged over 75 are most likely to want to die in a hospice but least likely to die in one[5].

It is important to ensure that everybody can access end of life care that is appropriate for their needs. Some groups of people, for example homeless people or Gypsies and Irish Travellers, are likely to find this much harder than others. Culture and language can also be barriers, for example some BAME people might have primarily experienced death as something that happens within the family and may not be aware of support that is available. Some LGB&T people say that they dread the thought of going into a care home because they fear they might not be accepted or feel they would have to come out all over again. People with conditions other than cancer may need to access specialist palliative care. Young adults with life-limiting conditions often find it hard to access adult services as they make the transition from childhood.

It is very important that local providers keep under constant review their reach and openness to ensure that they are accessible to everybody who might need their services.

What else to ask?

• Ask local end of life care services how many people they provide care for who have conditions other than cancer. What links do they have with services specialising in those conditions?

• Ask local providers how well they understand the demographic profile of the community they serve, and what steps they are taking to reach groups of people who may have found it hard to access services

Find out more

• The National End of Life Care Intelligence Network profiles
www.endoflifecare-intelligence.org.uk

• "Can you see me?" is a DVD presenting a kaleidoscope of people who are often invisible, including those who are homeless, from black, minority ethnic communities and who have conditions other than cancer. It describes end of life care needs, how to respond and ways to ask people what they want. Available at www.ncpc.org.uk

QUESTION 7
What training in end of life care are local organisations giving their staff?

Why is this important?

Although we all die and almost every health and social care professional will be involved in care of dying people at some point, end of life care is still not a core part of training curriculums, either pre-qualification or within continuing professional development. It is essential that end of life care be delivered by staff who are appropriately trained. They do not all need to be specialists in palliative care. However, they should all be trained in communication, symptom control (if in healthcare) and know who they can contact if additional care or advice is required.

There is considerable evidence that health and social care professionals do not feel sufficiently confident or trained in end of life care. For example:

• In 2012 a survey by the Royal College of Physicians showed that only a third of physicians had attended any learning event on end of life care in the last five years[6]. They were least confident in having discussions about advance care planning for people with dementia

• A survey of GPs in 2012 revealed that 35% had never initiated a conversation about end of life care with one of their patients[7]

• A survey in November 2010 found that 69% of nurses felt they did not have sufficient skills or time to talk to patients about dying, and 72% said that their anxiety around end of life care was due to a lack of training[8]

There have been many recent reports, most recently the Francis Report into Mid Staffordshire NHS Foundation Trust, of unacceptable care for people approaching the end of life. Core training in end of life care, with its focus on excellent communication, a holistic person-centred approach and good symptom control would help improve dignity and care for all, not just those at the end of life.

Training should not just be done pre-registration but as part of continuing professional development.

What else to ask?

• Who is commissioning training in end of life care locally?

• Ask the Local Education & Training Board ("LETB") and the Directors of Education & Quality what they are doing to improve end of life care training.

• What organisations locally provide end of life care training? Hospices very often have training and education departments, for example.

• If organisations do offer staff training in end of life care, who is it offered to, is it mandatory or optional and how long does it take?

• In addition to training, do organisations use values-based recruiting and appraisal as part of their workforce development policies?

Find out more

• Details of NCPC's confidence-building training can be found here
www.ncpc.org.uk/education-training

• The National End of Life Care Programme
www.endoflifecare.nhs.uk

QUESTION 8
Has end of life care been identified as a local priority and who is providing local leadership and accountability?

Why is this important?

The end of life is an inevitable stage in life; it is not a condition. End of life care is complex, and can be provided by many different organisations in different settings (for example acute hospitals, primary and community care, care homes, private dwellings) and sectors (the NHS, voluntary sector and independent sector all have important roles). It is very easy for end of life care to be forgotten or sidelined unless it is explicitly identified as a priority in local strategic documents and plans.

The Secretary of State's Mandate to the NHS Commissioning Board for 2013-14 identified end of life care as a key priority for the NHS, and so the Clinical Commissioning Groups (CCGs) which are responsible for commissioning local services should be including end of life care in their plans. Local Health and Wellbeing Boards (HWBs) have also been set up to work across health and social care to ensure local strategies meet the health and wellbeing needs of the community. End of life care affects the whole community and should be a priority for the HWBs.

In addition to ensuring end of life care is included in key plans (see below), it is also essential that local leads have been identified to be responsible and accountable for the development of end of life care.

It is important throughout to ensure that members of the public and people with personal experience are meaningfully involved in identifying local priorities for developing end of life care and shaping and evaluating services. This will help improve services and people's experience of care (see question 10).

What else to ask?

• What do the local Joint Strategic Needs Assessment and Health and Wellbeing Strategies say about end of life care?

• Has the local CCG, or CCG cluster, appointed an end of life care lead? Who is it?

• Has the local HWB appointed a lead for end of life care? Who is it?

• How are local people involved in producing strategies and developing services?

Find out more

• NCPC has produced a toolkit to help you understand the new organisations in the reformed NHS and the ways in which they can improve end of life care:
www.ncpc.org.uk/influencing-toolkit

• NCPC's report mapping which new Health and Wellbeing Boards have made end of life care a priority can be found here:
www.ncpc.org.uk/what-about-eolc

QUESTION 9
What local activities are being undertaken to raise public awareness about death, dying and bereavement and build people's confidence in having discussions and making plans?

Why is this important?

Our greatest fears are associated with death and dying. Polling shows that we are much more worried about dying alone, or in pain, or in hospital than we are about losing our job, bankruptcy, being divorced or facing the end of a long-term relationship[9]. This taboo becomes self-fulfilling: if we do not discuss and plan ahead for our end of life care, and make sure that our loved ones and care team know about our preferences, the things we are most frightened of are more likely to happen.

The Dying Matters coalition was set up by the National Council for Palliative Care as part of the End of Life Care Strategy to change public attitudes towards dying, death and bereavement, and to support people to have discussions and plan ahead in a more confident and better-informed way. Over 30,000 people and organisations have joined, not just within health and social care, but across a wide range of activities including financial services, law, major employers, schools, funeral providers, and pensioner's and retirement organisations. Death, dying and bereavement are not just about health and social care, although those are very important, but touch many other aspects of life as well including for example our work, finances, and friendships. Witnessing poor end of life care can have a significant impact on bereaved people and their ability to return to employment.

With more people dying in the community we need to find new ways to provide care and support for them, and not simply rely on medicalised models of care. It is therefore really important that there are local initiatives to help build people's confidence to discuss the end of life and think differently about how we support people approaching the end of life and their carers. It's very hard to change something if a taboo means we won't talk about it!

What else to ask?

• Ask the local Director of Public Health what they are doing to promote awareness about end of life care.

• Challenge all those involved in commissioning and providing care about whether they have spoken to anyone about their end of life wishes and preferences.

• Dying Matters holds an annual awareness week every May. Ask local end of life care organisations whether they are members of Dying Matters (it's free) and what they are doing in Dying Matters week.

Find out more

The Dying Matters website
www.dyingmatters.org

QUESTION 10

What steps are being taken to involve local people and those with personal experience in the way services are shaped and evaluated?

Why is this important?

End of life care seeks to serve the needs of local people and those with personal experience. It is therefore impossible to be sure that good care is provided without constantly asking those who use services:

• What does good end of life care look like?

• Which aspects of your experience would you describe as good?

• Which aspects of your care could and should we improve?

The new Clinical Commissioning Groups are required to involve local people and those with personal experience in their work. If the Government's phrase "Nothing About me Without Me" is to be made real, people with experience must be listened to if decision-makers are to understand how it feels to be or to care for someone who is nearing the end of life and what support and services they need to improve their experience at this vital time in their lives.

Involvement can empower people with personal experience by providing new skills, a 'voice' and a chance to 'give something back' or 'turn something negative into positive', at a time when they may have very little control.

In failing to involve people we waste resources; it is pointless investing time, money and energy providing end of life care if we're not sure that it is meeting people's needs and preferences.

What else to ask?

Whilst the concept behind involving people is straightforward, the practice can feel more difficult. The following questions will help you to assess the priority given and processes used in involving people (and therefore to getting services right).

• How is support for involving local people and those with personal experience demonstrated by those with responsibility for planning and delivering services? For example, chief executives, senior managers and commissioners. Without commitment from the top, it is unlikely to happen at grass roots level.

• Is there a named person with authority, responsibility, resources and budget for leading on involvement? If not, it is unlikely that people will take ownership of this important area of work.

• Is the organisation flexible in its approach to involvement, ensuring that people can be involved as much or as little as they wish to, regardless of their physical health, personal and work commitments.

• Are those who are involved valued and satisfied that they are listened to and can make a meaningful contribution, and are not there simply to 'tick a box'.

• How is the impact of involving people evaluated and communicated? It is essential to do this to ensure that organisations constantly learn how to improve on the way that they involve people and can accurately share the impact with those who are involved.

Find out more

Health and Social Care Act 2012

NCPC - Getting started www.ncpc.org.uk

NCPC - Guide to involving patients, carers and the public in palliative and end of life care www.ncpc.org.uk

Acknowledgements

References

[1] ComRes survey for Dying Matters, 2012

[2] Office for National Statistics National Bereavement Survey (VOICES), 2011 www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/stb-statistical-bulletin.html

[3] Palliative Care Funding Review (2011)

[4] The Minimum Data Set (MDS) for Specialist Palliative Care Services www.ncpc.org.uk/mds

[5] *Local preferences and place of death in regions within England 2010* Gomes et al (2011) Cicely Saunders International

[6] *Improving end-of-life care: professional development for physicians* (2012) Royal College of Physicians

[7] Ibid

[8] *Nursing Times*, 30 November 2010

[9] ComRes survey for Dying Matters, 2012

About

The National Council for Palliative Care

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.

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

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Marie Curie Cancer Care

Marie Curie Cancer Care provides end of life care to people in their place of choice. Last year the charity cared for more than 35,000 terminally ill patients through the Marie Curie Nursing Service in the community and in its nine hospices. The charity also designs and advises on end of life services to ensure that the best possible care and patient choice is at the heart of commissioning end of life care across the UK. www.mariecurie.org.uk/healthcare-professionals

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