



Marie
Curie

Care and support
through terminal illness

Changing the conversation

Care and support for people with a
terminal illness now and in the future

April 2015

Terminal illness is changing

Today, one person in the UK dies every minute.

Year on year, more people in the UK are dying as our population ages.

Over the next 25 years, the number of deaths will increase by around 100,000 more deaths each year¹.

That's one more person dying every five minutes.

Most of these people will have been living with a terminal illness, whether that's terminal cancer or any other illness. By that, we mean they will have reached a point where their illness is likely to lead to their death. Depending on their condition and treatment, they may live with their illness for days, weeks, months or even years after this point. They will probably have needed care and support for all or part of that time.

Because life expectancy is increasing, people with a terminal illness are living with more complex needs than before. Indeed, they will often have multiple long-term conditions. As we saw last winter, there are already huge pressures on services to provide the care that people need.

Every day matters when you're living with a terminal illness. People want to be able to get the most from the time they have left. Part of that is about people feeling able to talk to their doctors, nurses, family and friends about the sort of care they would like and the things they want to do. It matters that the people they are talking to be skilled in having these important conversations.

Our work, as well as that of organisations such as Dying Matters in England, Good

Life, Good Death, Good Grief in Scotland, the All Ireland Institute of Hospice and Palliative Care in Northern Ireland and Byw Nawr in Wales, is helping the public think and talk more about terminal illness. This has government support, with all four UK governments producing strategies to improve care for people with a terminal illness². But more work still needs to be done to make it a reality.

The UK is considered a world leader in supporting people living with a terminal illness³. But carers say seven out of every 10 people with a terminal illness in the UK do not get all the care and support they need^{*4}.

If that's the case now, what happens when there's one more person dying every five minutes?

We believe the conversation needs to move on urgently if we are to meet the growing challenges, especially as the post-war generation moves beyond retirement age. Policy makers, health and social care professionals, service planners and communities must talk honestly about what sort of care and support we want to give people affected by terminal illness when their needs are becoming more complex, are often being unmet and are set to grow in number.

^{*}Ipsos MORI survey of 1,067 UK carers aged 16-75

We need to be ready for unprecedented demands

People with a terminal illness are living with more complex needs and often multiple long-term conditions

Advances in medicine and care coupled with the adoption of healthier lifestyles mean people now live longer. However, they are more likely to develop multiple long-term conditions (known as multimorbidities).

People with multimorbidities tend to experience poorer quality of life. They are much more likely to have unplanned and undesirable hospital admissions that could have been prevented⁵. It is also much harder to predict when they are approaching the end of their life, presenting new challenges to planning their care when they become terminally ill.

Forty-four per cent of adults in the last year of life have multiple long-term conditions⁶. The number of people in England with at least three multimorbidities is expected to have risen from 1.9 million in 2008 to 2.9 million by 2018⁷. In Northern Ireland, the number of adults living with a long-term condition is expected to increase by 30% by 2020⁸.

We can expect similar increases throughout the UK.

A good indication of how well someone's care is being managed

is how often they are admitted to hospital as an emergency. In England, people in the last year of life have an average of 1.5 emergency admissions, and on average spend a total of 22 days in hospital following those admissions⁹. In Wales, it was typically just under 23 days¹⁰ and people in Scotland in the last six months of life spent anywhere between 10 and 22 days in hospital¹¹. Unfortunately, this data is not currently available for Northern Ireland.

There are a number of factors which make it harder for certain groups to access care. This can be down to the particular illness you have. For example, people with degenerative conditions such as dementia, chronic obstructive pulmonary disease (COPD) or heart failure are less likely to be referred to a palliative care unit than those with terminal cancer^{13, 14}.

This is partly because the roots of the modern hospice and palliative care movements developed in response to the needs of people with cancer. We know, however, that palliative care can significantly benefit people with a whole range of terminal conditions.

Factors completely unrelated to your illness can also affect how easy it is for you to get the care you need¹⁵. Access to suitable or appropriate care can be more difficult if you have a disability¹⁶, if you are from a Black or Minority Ethnic background¹⁷ or if you are LGBT¹⁸. The same is true if you're homeless¹⁹, in prison²⁰, or you're from a deprived area²¹.

Many of the needs of people with a terminal illness and their families are unmet and unrecognised, and significant inequities exist in the system

Carers say seven out of every 10 people with a terminal illness in the UK do not get all the care and support they need¹².

People have more complex needs

The number of people in England with at least three long-term conditions is expected to have risen from

1.9 million
2008

2.9 million
2018

44%
of adults

in the last year of life have multiple long-term conditions



Source: see notes 6 and 7

Carers say

7 out of 10 people



with a terminal illness don't get all the care and support they need

Source: see note 4

There will be a dramatic increase in the number of people living with a terminal illness in the coming years

At present, every year around 470,000 people die in England²², 54,700 people in Scotland²³, 32,000 in Wales²⁴ and 15,000 in Northern Ireland²⁵. Over the next 25 years, this is set to increase by about an extra 100,000 people dying each year across the UK²⁶.

We know that about three quarters of these people will need and benefit from some form of palliative care^{27, 28}.

Those who are in the last year of their life already account for 9.4 million NHS bed days in England²⁹ and nearly a quarter of all bed days (over a million) in Wales are occupied by someone who is

in their last year of life³⁰. About half of all deaths still occur in hospital in each of the four nations of the UK³¹.

Other research suggests that almost three in every 10 hospital inpatients are in their last year of life³². Around 15% of all emergency hospital admissions in England belong to the 1% of people in their final year of life³³.

If existing services cannot meet the current needs and there is no change, then this growth in numbers of people dying will lead to even greater unmet needs.

Number of deaths each year in the UK



People with a terminal illness and their families feel they don't get the right support

Care for people living with a terminal illness should be based on what individuals and their families need, rather than what works best – or is easiest – for the health and social care system to provide.

Sometimes it isn't even necessary to make a choice between the two. For example, most people want to be cared for in their own homes at the end of their life. Providing more services in the community will reduce pressure on hospital beds, meet people's wishes and has the potential to be a more efficient and effective use of NHS resources. But even so, investment remains very much focussed on acute services in a hospital environment.

“To begin with you don't really know what you're looking for. You don't know what things you want to find out until you actually sit and talk to someone who can understand³⁴.”

We speak to people living with a terminal illness and their families every day. This is what they tell us:

It's an isolating and confusing experience

Many people with a terminal illness and their families feel they cannot get the information and support they need to help them through an extremely difficult time. Often they are uncertain where to go for help and who to ask about the many different issues that they may face.

This is often made worse by professionals struggling to communicate with them clearly, particularly when talking directly about the fact that someone is going to die.

If professionals do not provide the appropriate information, people may feel unsure about what services they need and unable to make decisions that benefit them.



Simon Rawles/ Marie Curie

“He was still having radiotherapy... doctor was saying ‘Well I wouldn’t rule out another stem cell transplant.’ He told him that two weeks before he died... and it was giving him the wrong signals... he was clutching at straws”

[Bereaved carer – partner with cancer]³⁵

It is an unequal system

Research shows that people with a terminal illness do not have equal access to the care they need³⁸. They and their families are well aware of this.

“My overwhelming impression is that there’s lack of consistency. It all depends where you live.”

[Bereaved carer – daughter with cancer]³⁹

Some carers report feeling unsupported and left out of conversations about their loved one’s care³⁶, as well as finding a lack of information to help them prepare for the reality of a loved one dying at home and support after bereavement.

More and more people will also potentially be facing terminal illness without the support of a carer, as the number of people living alone increases. In Northern Ireland, for example, it’s estimated that a third of people over the age of 65 will be living alone by 2020³⁷.

People living with a terminal illness also feel the care and support available to them is inconsistent between different places of care. Bereaved carers also report a lower quality of care in hospitals than at home or in a hospice⁴⁰.

It is important that services are provided that people feel comfortable using, otherwise they may find it difficult to see the benefit.

“I didn’t belong in terms of what I felt like age-wise, disability-wise, because I was still walking - and so what I saw was lots of people in wheelchairs, lots of people over the age of 50 or 60 and I was 20-something. And also I didn’t see anybody from a different ethnicity, so it was predominantly white...male, 50s and 60s...in some ways I left feeling more isolated”

[Terminally ill person with MS on a support group]⁴¹

It is too difficult to get care when it is needed

For many families, nights and weekends can be worrying times because of a lack of accessible, personal or effective out-of-hours care in their area. Despite improvements in some areas, access to this care is inconsistent across the UK. People living with a terminal illness, carers and health and social care professionals tell us that out-of-hours care and equal UK-wide provision of care are the two major areas they would like to see more research in.⁴³

“I did feel a bit abandoned and a bit scared... the middle of the night is a very terrifying place to be in when you’re not sure what to do”

[Bereaved carer – husband with cancer]⁴²

“Before even checking the patient out a lot of times they just go, ‘hospital’, because they are too scared to deal with that patient, with all the tablets and the conditions they’ve got⁴⁴.”

People who have had negative experiences of out-of-hours care in the past may be reluctant to use those services again. People say they are afraid to see a different doctor, who is not familiar with their needs, wishes or illness, as they worry this may result in an unwanted hospital admission.

Ineffective coordination of care between services such as health and social care or general and out-of-hours practice, and between different organisations, can lead to unnecessary delays for care and support. Evidence in England suggests that this problem is getting worse, as between 2012 and 2013, the VOICES survey of bereaved relatives shows a significant fall in ratings for service coordination.

We must change the conversation about terminal illness

Everyone living with a terminal illness should have access to high quality care and support, which meets all of their needs.

Our already stretched health and social care system is failing to deliver that now and the demands on it are only set to grow.

So we need a conversation that tackles the big issues and finds solutions:

- We need to discuss how we are going to **find the resources** to care for increasing numbers of people with a terminal illness who have increasingly complex needs.
- We need to make sure we do so in a way that **allows people to choose** where and how they will live towards the end of their life.
- We need to decide how we are going to **support families and communities** so they can give people living with a terminal illness the care and support they want.
- We need to make sure that if you have a terminal illness, you get the **same quality and ease of access to care**, regardless of who you are, where you live or what your illness is.

- We need to discuss how professionals will get all the **training and support** they need to provide high quality, person-focused care.

We need everyone to take part in this conversation, including people who have a terminal illness themselves or are supporting a loved one, health and social care professionals, service planners and policy-makers.

This issue affects us all. It's likely to touch most families in the UK in the coming years. We may not like to think about it in this way, but the reality is that we will all die. So when we talk about care and support through terminal illness, what we're talking about is the life we want for our families. Our loved ones. Ourselves.

The conversation about terminal illness must change. If it doesn't, we as a society will be failing vulnerable people at the time they need us most.



Simon Rawles/ Marie Curie

Endnotes

- 1 ONS (2014). 2012-based National Population Projections.
- 2 *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life* (Department of Health, England, 2008); *Together for Health, Delivering end of life care. A Delivery Plan up to 2016 for NHS Wales and its partners* (NHS Wales, 2013); *Living and Dying Well: A National Action Plan for End of Life Care in Scotland* (Scottish Government, 2008); and *Living Matters, Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland* (Department of Health, Social Services and Public Safety Northern Ireland, 2010)
- 3 Economist Intelligence Unit (2010). *The quality of death: Ranking end-of-life care across the world*. The Economist, 14 July 2010, p. 6.
- 4 On behalf of Marie Curie, Ipsos MORI interviewed a quota sample of 1,067 adults aged 16-75 online who had cared for a family member, friend or neighbour who was, or is, terminally ill in the last 3 years. This sample was screened from a nationally representative sample of 6,136 online adults aged 16-75 within the UK. Interviews took place between across the UK using i:omnibus, Ipsos MORI's online omnibus between 3rd and 29th October 2014. Data are weighted by age, gender, region, working status and social grade to match the profile of the target audience.
- 5 Payne, R. A. et al. (2013). *The effect of physical multimorbidity, mental health conditions and socioeconomic deprivation on unplanned admissions to hospital: a retrospective cohort study*. Canadian Medical Association Journal, March 19, 2013, vol. 185 no.5.
- 6 Nuffield Trust, 2015, Individual correspondence with Marie Curie (data available on request). Cohort of 73,243 adults as defined in Nuffield Trust 2012 report: "Understanding patterns of health and social care at the end of life", List of chronic (long term) conditions: Diabetes, Hypertension, Congestive heart failure, COPD, Ischaemic heart disease, Asthma, Angina, Cerebrovascular disease, Connective tissue disease/rheumatoid arthritis, Sickle cell disease, Renal failure, Cancer and Dementia. Chronic (long term) conditions are assigned to individuals by scanning all inpatient diagnoses recorded during the last two years of life.
- 7 Department of Health (2012). *Long Term Conditions Compendium of Information – Third Edition*. 30 May 2012.
- 8 DHSSPS – Living with Long Term Conditions – A Policy Framework, April 2012 & Institute of Public Health in Ireland – Making Chronic Conditions Count, February 2010.
- 9 *Understanding patterns of health and social care at the end of life*, Nuffield Trust, 2012
- 10 Marie Curie and the Bevan Foundation (2014). *Death and dying in Wales*.
- 11 ISD Scotland (2014). *Percentage of End of Life Spent at Home or in a Community Setting: Financial years ending 31 March 2009 to 2013*. August 2014.
- 12 See note 4.
- 13 Gardiner, C. et al (2011). *Barriers to providing palliative care for older people in acute hospitals*. Age & Ageing, 40 (2). pp. 233–238.
- 14 Marie Curie and the Alzheimer's Society (2014). *Living and dying with dementia in England: Barriers to Care*. December 2014
- 15 Dixon J. et al. (2015). *Equity in the provision of palliative care in the UK: Review of evidence*. Personal Social Services Research Unit, LSE. March 2015.
- 16 Marie Curie Policy and Public Affairs (2014). *The experiences of caring for disabled people at the end of life*. Marie Curie, 2014 [unpublished]
- 17 Calanzani et al (2013). *Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK: Demographic profile and the current state of palliative and end of life care provision*. June 2013.
- 18 Fuller et al (2011). *Open to all? Meeting the needs of lesbian, gay, bisexual and trans people nearing the end of life*. National Council for Palliative Care, Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations.
- 19 Davis et al (2011). *Are the homeless dying without access to palliative care?* BMJ 2011;342:d3018.
- 20 Peacock (2014). *Dying in prison: 'Both sides of the fence' study*. eHospice, 12 June 2014. Online at – <http://www.ehospice.com/uk/ArticleView/tabid/10697/ArticleId/10878/language/en-GB/View.aspx>
- 21 Barnett et al (2012). *Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study*. The Lancet 2012 Jul 7;380(9836):37-43
- 22 Office of National Statistics (2014). *Deaths in England and Wales, 2013, Part of Death Registrations Summary Tables, England and Wales, 2013 Release*.
- 23 General Registrar Office for Scotland (2013). *Vital Events Reference Tables: Table 5.4 Deaths by sex, age, and ethnic group, Scotland 2013*.
- 24 Office of National Statistics (2014). *Deaths in England and Wales, 2013, Part of Death Registrations Summary Tables, England and Wales, 2013 Release*.
- 25 Northern Ireland Statistics and Research Agency (2013). *Deaths in Northern Ireland, 2013/ Additional tables for Deaths in Northern Ireland, 2013* <http://www.nisra.gov.uk/demography/default.asp23.htm>
- 26 ONS (2014). 2012-based National Population Projections.
- 27 Murtagh FEM, Bausewein C, Verne J, Groeneveld EI. (2014). *How many people need palliative care? A study developing and comparing methods for population-based estimates*. Palliative Medicine, January 2014, vol 28, no. 1, pp 49–58
- 28 Moens K, Higginson IJ, Harding R (2014). *Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review*. Journal of Pain and Symptom Management. 2014 Oct; 48(4) pp. 660–77.
- 29 National End of Life Care Intelligence Network (2012). *What do we know now that we didn't know a year ago? New intelligence on end of life care in England*, p. 10.
- 30 Marie Curie and the Bevan Foundation (2014). *Death and dying in Wales*.
- 31 ONS (2014) *Deaths: area of usual residence and sex, by place of occurrence, numbers and percentages, 2013*. England and Wales; *Deaths, by sex, cause and place of occurrence and whether post mortem performed*, Scotland, 2012 provided by the General Register Office for Scotland; NISRA (2013) *Statistical Bulletin: Death in Northern Ireland 2012*.
- 32 Clark D et al. (2014). *Imminence of death among hospital inpatients: Prevalence cohort study*. Palliative Medicine 28 (6) pp. 474–479. June 2014.
- 33 <http://www.nuffieldtrust.org.uk/blog/counting-cost-end-life-care>
- 34 Cragg et al. (2014) Marie Curie. *Feedback on focus group on Information and Support Service*. [Internal document]
- 35 Marie Curie Policy and Public Affairs (2014). *Difficult conversations with dying people and their families*. Marie Curie, March 2014
- 36 Office of National Statistics (2014). *National Survey of Bereaved People (VOICES)*, 2013. July 2014.
- 37 Transforming Your Care – A Review of Health & Social Care in Northern Ireland, December 2011.
- 38 Dixon J. et al. (2015). *Equity in the provision of palliative care in the UK: Review of evidence*. Personal Social Services Research Unit, LSE. March 2015.
- 39 Marie Curie Policy and Public Affairs (2014). *Difficult conversations with dying people and their families*. Marie Curie, March 2014
- 40 Office of National Statistics (2014). *National Survey of Bereaved People (VOICES)*, 2013. July 2014.
- 41 Marie Curie Policy and Public Affairs (2014). *Difficult conversations with dying people and their families*. Marie Curie, March 2014
- 42 ibid
- 43 James Lind Alliance (2015). *Palliative and end of life care Priority Setting Partnership*.
- 44 Worth et al (2006). *Out-of-hours palliative care: a qualitative study of cancer patients, carers and professionals*. The British Journal of General Practice, January 1 2006; 56(522); 6–13

We need everyone to take part in this conversation, including people who have a terminal illness themselves or are supporting a loved one, health and social care professionals, service planners and policy-makers.

This issue affects us all. It's likely to touch most families in the UK in the coming years. We may not like to think about it in this way, but the reality is that we will all die. So when we talk about care and support through terminal illness, what we're talking about is the life we want for our families. Our loved ones. Ourselves.



The conversation about terminal illness must change. If it doesn't, we as a society will be failing vulnerable people at the time they need us most.

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

mariecurie.org.uk



MarieCurieUK



@MarieCurieUK

@MarieCurieEOLC

@MarieCuriePA



Care and support
through terminal illness