Changing the conversation
Care and support for people with a terminal illness now and in the future
April 2015
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 illness. 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 illness. 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. 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.
We need to be ready for unprecedented demands

Forty-four per cent of adults in the last year of life have multiple long-term conditions. 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 2018. In Northern Ireland, the number of adults living with a long-term condition is expected to increase by 30% by 2020.

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 admissions. In Wales, it was typically just under 23 days and people in Scotland in the last six months of life spent anywhere between 10 and 22 days in hospital.

Unfortunately, this data is not currently available for Northern Ireland.

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. 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.

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 need. Access to suitable or appropriate care can be more difficult if you have a disability, if you are from a Black or Minority Ethnic background or if you are LGBT. The same is true if you’re homeless, in prison, or you’re from a deprived area.

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

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 prevented. 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.

People have more complex needs

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At present, every year around 470,000 people die in England\(^\text{22}\), 54,700 people in Scotland\(^\text{23}\), 32,000 in Wales\(^\text{24}\) and 15,000 in Northern Ireland\(^\text{25}\). Over the next 25 years, this is set to increase by about an extra 100,000 people dying each year across the UK\(^\text{26}\).

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

Those who are in the last year of their life already account for 9.4 million NHS bed days in England\(^\text{29}\) and nearly a quarter of all bed days (over a million) in Wales are occupied by someone who is in their last year of life\(^\text{30}\). About half of all deaths still occur in hospital in each of the four nations of the UK\(^\text{31}\).

Other research suggests that almost three in every 10 hospital inpatients are in their last year of life\(^\text{32}\). Around 15% of all emergency hospital admissions in England belong to the 1% of people in their final year of life\(^\text{33}\).

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.
Why we must change the conversation about terminal illness

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.

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.

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.

“**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 understand**”.

Simon Rawles / Marie Curie
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.

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.

It is an unequal system

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

Some carers report feeling unsupported and left out of conversations about their loved one’s care, 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 2020. 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 hospice.

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

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Why we must change the conversation about terminal illness

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-focussed 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.
Endnotes


2 2nd of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life (Departments of Health, England, 2008); Together for Health. Delivering end of life care. A Delivery Plan up to 2016 (for NHS Wales and its partners (NWAS, 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 Economic Intelligence Unit (2010). The quality of death: Analysing 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 terminal, in the last 3 years. This sample was screened from a nationally representative sample of 5,136 online adults aged 16-75 within the UK. Interviews took place between across the UK using 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.


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.


10 Marie Curie and the Bevan Foundation (2014). Death and dying in Wales.


12 See note 4.


18 Fuller et al (2013). 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.


23 General Registrar Office for Scotland (2013). Visit Events Reference Tables: Table 5.4 Deaths by sex, age, and ethnic group, Scotland 2013.


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.


34 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.


37 Transforming Your Care – A Review of Health & Social Care in Northern Ireland, December 2011.


42 ibid


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