

Triggers for palliative care

Improving access to care for people
with diseases other than cancer

Executive summary

June 2015



Care and support
through terminal illness

Foreword

Each of our organisations, in different ways, has recognised the importance of providing the right care and support for people living with a terminal illness. We also recognise that much remains to be done to ensure that everyone who could benefit from palliative care gets it. Palliative care specialists, as well as general practitioners, nurses and specialists in other specialities all have a role to play in that care.

We also know that as we all live longer there will be greater complexity of need in the last days, months and years of life. This, together with the projected rise in numbers of people dying over the next couple of decades, reinforces the importance that providing care and support to people with terminal illness must have in our thinking and actions.

The members of our organisations have some of the solutions in their hands, but not all. We will need to work with others who are responsible for setting policies and strategies and for planning and commissioning services; we will need to work with clinical colleagues and people working in other public services as well as the voluntary sector; we will need to engage with patients and their families about how, where and when clinical care and support is provided, and above all else our work and leadership must be focused on the quality of life we can support right up to the point when someone dies.

It's for all these reasons that we welcome Marie Curie's wish to see the conversation about terminal illness change and support their desire to make it happen.



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Introduction

At Marie Curie, we believe that everyone living with a terminal illness should be able to access the care they need, when they need it.

Whether it's terminal cancer or any other terminal illness, we provide care and support to help people get the most from the time they have left.

Earlier this year, we commissioned the Personal Social Services Research Unit at the London School of Economics and Political Science (LSE) to undertake a review of inequities in palliative care. This found access to high quality palliative and end of life care is affected by factors including the condition a person has. In particular, people with a terminal condition other than cancer often miss out on getting care when they need it.

We think this needs to change.

Palliative care is the active, holistic care of people with advanced progressive illness, involving management of pain and other symptoms and the provision of psychological, social and spiritual support. It aims to help people with advanced illnesses or at the end of their lives have the best possible quality of life. Palliative care can benefit people with many different illnesses and at different stages in those illnesses.

Our latest report, *Triggers for palliative care*, which builds on the LSE's work is summarised below. It reviews existing research to find out why this inequity

occurs and what can be done to change it. We want to know why people with some of the most prevalent terminal illnesses – such as heart failure, chronic obstructive pulmonary disease (COPD), dementia, end stage liver disease and motor neurone disease – are not able to get the care and support they need. People living with multiple sclerosis, Parkinson's disease and those who have had an acute stroke also face many of the same issues.

The report offers those responsible for developing policies and delivering services the opportunity to test them against some key research findings. It doesn't comment on the policies of any particular UK nation or on services in one hospital or another.

However, as well as the main report and this summary, we have produced brief reports for England, Scotland, Wales and Northern Ireland which set the findings in a nation specific context. These reports include recommendations which take account of the prevailing palliative care and disease environment.

Read the full report and brief reports for the four UK nations at mariecurie.org.uk/change

People living with different terminal illnesses are not accessing palliative care when they need it because...

1. ...some conditions have an uncertain trajectory

When someone has an incurable form of cancer, their illness will typically progress steadily and clinicians will be able to identify a clear terminal phase (Murray et al, 2005). For people living with other terminal illnesses, the trajectory of their illness may be much harder to predict. This may complicate professional decisions about when to introduce palliative and end of life care.

For example, there is often no clear terminal phase in the progression of liver disease (Boyd et al, 2012). Similarly, it might be more difficult to identify when someone living with COPD is approaching the end of their life than it is for someone who has lung cancer (Chou et al, 2013). Multiple sclerosis often develops over many years with fluctuating levels of symptom intensity (NEoLCP, 2011).

Yet for people with these conditions, research shows that introducing timely palliative care has considerable benefits. It may be appropriate to have on-going but episodic involvement of palliative care at the same time as active treatment, rather than the

traditional model where palliative care is introduced as the person approaches the end of life.

2. ...some conditions are not recognised as terminal

Someone has a terminal illness when they reach a point where their illness is likely to lead to their death. Depending on their condition and treatment, they may live for days, weeks, months or even years after this point.

However, we know that many conditions that fit this definition are still not generally recognised as being terminal. This can lead to people missing out on palliative care.

For example, the Scottish Partnership for Palliative Care (2008) suggests that wider recognition of heart failure as a terminal condition, which adversely impacts on quality of life, would lead to better palliative care provision.

Research also suggests that a lack of dementia training for staff in places where people receive palliative and end of life care may partly explain why dementia is often not thought of as a terminal illness (Alzheimer's Disease

International, 2013). Parkinson's disease is another condition which is not usually recognised as being terminal. Tuck et al (2015) argue this may complicate decisions about when to help people with Parkinson's begin advance care planning (ACP), even though research shows it is best to introduce this early on.

3. ...people don't always understand what palliative care is and what it can achieve

The historic links between palliative care, hospice care and cancer may discourage practitioners caring for people with other terminal conditions from making referrals to these services (Berry, 2010; Golla et al, 2014).

Healthcare professionals may also be reluctant to introduce palliative care because they perceive a palliative care approach as giving up on the patient. They may prefer aggressive treatment which aims to prevent death rather than increase quality of life (Kavalieratos et al, 2013). For conditions which develop over a long time, such as multiple sclerosis, professionals may not think palliative care is relevant to their patient's care (Golla et al, 2014).

People living with terminal conditions may be afraid to talk about palliative care because they associate it with imminent dying, or they might reject it altogether (Golla et al, 2014). Knowledge that palliative care can be delivered alongside active treatment may be limited, for example for people with COPD who are awaiting lung transplants (Colman et al, 2013).

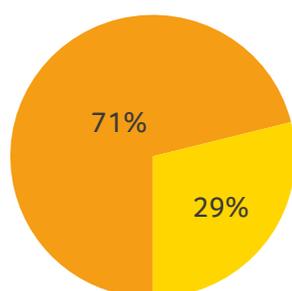
4. ...there hasn't been much research about the benefits of palliative care for people with certain conditions

Much of the literature relating to palliative and end of life care relates to research into different forms of cancer. This reflects the fact that 12% of people in England, Wales and Northern Ireland using palliative in-patient services have a diagnosis other than cancer, even though diseases other than cancer currently account for more than two-thirds of deaths in England and Wales. (NCPC, 2014).

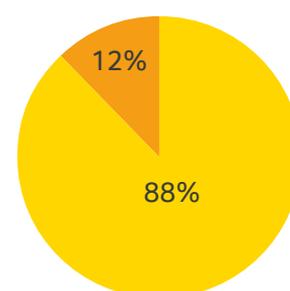
We know there are also differences between the levels of available research for different non-malignant conditions (ie conditions other than cancer). Areas which need more research include:

Disparity in access to palliative care

Total number of deaths in England and Wales 2012



People receiving palliative care in specialist in-patient units in 2012-13



Source: see notes 3 and 4

“Although my husband was quite poorly, we were not offered any palliative care support. The only day that we had any dealings with the palliative care team was on the day before he died...I wish there was more communication, and earlier in time, to help us prepare for the end and to discuss his last wishes.”

Woman whose husband died of end stage liver disease

outcomes of palliative interventions for people with COPD (Weber et al, 2014); appropriate palliative approaches for people with end stage liver disease (Iredale, 2008); and the palliative care needs for people who have had an acute stroke (Burton et al, 2010).

5. ...professionals don't feel confident in delivering the care that people need

Many studies show that healthcare professionals lack confidence in making decisions and communicating with people about their care as they approach the end of their life. Sometimes, this can result in the person living with a terminal illness not realising the seriousness of their condition when in fact they would have welcomed having more open conversations about it (Barclay, 2001).

One study found that less than half of GPs always or often discussed prognosis with their patients living with COPD. Two-thirds of those GPs said they felt inadequately prepared to have these discussions (Elkington et al, 2001). This is despite evidence which suggests some patients with COPD wanted more

information about their diagnosis, treatment options, what dying might be like and advance care planning (Curtis et al, 2002).

We know there may be further challenges for professionals who are caring for people with conditions such as dementia, which involve progressive cognitive impairment. In this instance, it is all the more important to support the person to make their wishes known as early as possible, if they choose to. Staff may also feel unsure about whether acting in line with advance decisions is right or legal, especially if this involves stopping active treatment (Sampson et al, 2012).

6. ...links between professionals who care for people with specific conditions and palliative care specialists are underdeveloped

In contrast to the strong links which often exist between specialist palliative care teams and cancer services, in some other clinical specialisms these relationships still need to develop. For example, we know from research by University College London, funded by Marie Curie, that there are weak links between liver specialists and palliative care (Davis et al, 2015). Research from this project also found that referrals to palliative care services tend to happen in the last few days of life for people with end stage liver disease.

Research also shows that healthcare professionals are sometimes confused about whose role it is to talk to patients about their wishes and preferences for care (Dunlay et al, 2015).

Research shows certain things can act as ‘triggers’ which indicate that a palliative care approach is appropriate, such as when someone...

1. ...has complex or persistent problems with managing symptoms such as pain or breathlessness

Someone living with a terminal illness may experience a wide range of problems or symptoms which palliative care could help them to manage, so they can have a better quality of life, regardless of what stage of their illness they are at. These include pain, breathlessness, nausea, vomiting, difficulty sleeping, as well as psychosocial problems such as anxiety and depression. Decisions about introducing palliative care should be based on the present needs and preferences of the person.

2. ...has high levels of unplanned hospital use

When someone has a condition which has an uncertain prognosis, high levels of unplanned hospital use can indicate that they are approaching the end of their life. This could provide an opportunity to discuss advance care plans and future preferences for treatment. Research supports using this indicator for many different conditions, such as heart failure

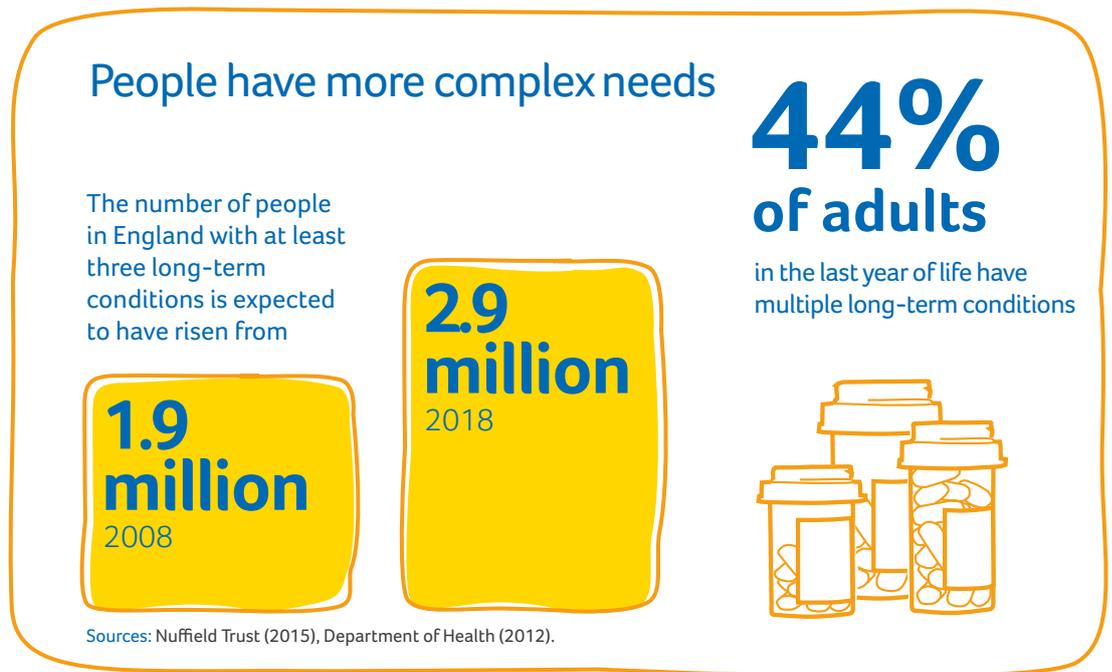
and COPD (D’Elia, 2013), end stage liver disease (Boyd et al, 2012) and dementia (Sampson et al, 2012).

3. ...has more than one condition to manage

We know that 44% of adults in the last year of life have multiple long-term conditions, or ‘multimorbidities’ (Marie Curie, 2015). As the population of the UK ages, the number of people living with more than one long-term condition is set to increase. People who have multiple complex conditions already often experience poorer health outcomes than those who are managing a single condition, with more hospital admissions and longer in-patient stays (Smith et al, 2012). Someone who has a terminal diagnosis and is also managing other complex conditions is likely to benefit from the holistic support palliative care provides.

4. ...has changes in eating habits and nourishment

Changes in eating habits may provide a clear indication that someone with dementia is approaching the



end of their life. Decreased appetite, malnutrition and weight loss, as well as having a dry mouth, are established indicators (Brown et al, 2012).

5. ...has new clinical interventions introduced

Sometimes people will develop swallowing or breathing problems as a result of their illness, which may mean they require a feeding tube or ventilatory support. Introducing palliative care may be appropriate when new interventions are started (NEoLCP, 2011) and may be episodic as the person's needs change over time.

6. ...is diagnosed with a particular condition

Motor neurone disease typically progresses quickly and has a trajectory similar to terminal cancer. Introducing palliative care and having conversations about treatment preferences at the point of diagnosis, or as soon as sensitively possible, is recommended (APPG on MND, 2011). Even for conditions with a slower or more

uncertain trajectory, it is often beneficial to involve palliative care earlier.

7. ...has high levels of palliative care needs as indicated by an appropriate screening tool

Palliative care screening tools can help identify people with high levels of palliative care needs. For example the Sheffield Profile for Assessment and Referral to Care (SPARC), which assesses factors such as pain, fatigue, symptom management and psychological distress, has been shown to be effective (Burton et al, 2010). Another widely applicable clinical tool is the Supportive and Palliative Care Indicators Tool (SPICT), which has been designed to support improved care by those providing general supportive and palliative care for their patients.

The Palliative Care Outcome Scale (POS) can also be used to identify unmet need for specialist palliative care. It has been adapted for effective use with various conditions such as Parkinson's disease (Saleem et al, 2013).

To ensure that everyone with a terminal illness gets the care they need when they need it, things need to change...

1. Using the right triggers

Decisions about care should, above all, be about meeting people's holistic needs so they can have the best quality of life in the time they have left. Palliative care is shown to be effective in achieving this.

For many terminal conditions, the traditional prognosis-based approach to making palliative care referrals is inappropriate. The referrals process should focus on the person, their experiences of their illness and their present needs.

Using appropriate triggers (listed above) can help health professionals identify when these needs might require a palliative care approach. This may involve adopting a more dynamic approach to reflect the fluctuating nature of many conditions.

2. Changing perceptions about palliative and hospice care

We know that inappropriate perceptions about what palliative care is and when it is suitable can prevent or delay referrals. People living with a terminal illness, their carers and health professionals have all been found to misunderstand

what palliative care is and how it can support people. Similarly, the diversity of services offered within hospices is often not understood (Bradley et al, 2011). Campaigns to promote timely access to palliative care must recognise that professional and public understanding will be key to achieving this.

3. Achieving appropriate referrals practices

We know that earlier access to palliative care helps to support advance care planning, support patients and their families and promote better symptom management (Charnock et al, 2014). A number of factors beyond clinical need can influence professionals' decisions about making referrals, including their perceptions of what other teams can provide. Targeted training, education and using appropriate referral criteria could all help ensure people get access to palliative care as soon as they need it.

4. Making palliative care everyone's business

Palliative care is delivered by a wide range of professionals across a range of settings. These include GPs, geriatricians and cardiologists, not just palliative care specialists. It

is also important that patients and their families are supported to have a genuine role in decisions about their care.

There are many condition specific implementation frameworks and guidelines for each of the UK nations which set out what best practice for caring for people living with a terminal illness should look like. It is important that policy aspirations become reality.

5. Better coordination and team working

We know that strong links and effective coordination with specialist palliative care teams can help clinical specialists ensure appropriate care for their patients. A multidisciplinary and integrated approach to care is in line with strategies from each of the UK governments. Unfortunately, this isn't always the reality and needs to change.

Where good coordination and team working exist, this best practice needs to become the norm. We need to identify examples of where this has worked well to help spread this best practice. One example is a collaboration between British Heart Foundation Heart Failure Specialist Nurses, Marie Curie Nurses and Healthcare Assistants, and primary care teams which resulted in more comprehensive end of life care in the community (British Heart Foundation, 2010).

6. The important role of nurse specialists

We know that clinical nurse specialists can provide a crucial support and they are an effective means of ensuring their patients are able to access the best

package of care for them. Heart failure nurse specialists, in particular, have been shown to routinely provide much of the palliative care their patients need (British Society for Heart Failure, 2013). We need to understand whether this is also the case for people with other terminal conditions and to support nurse specialists to carry out this important role.

7. Improving palliative care across all settings

Even though levels of care in the community are improving, the majority of deaths from conditions other than cancer occur in hospital. In Scotland, nearly a third of hospital in-patients are likely to be in their last year of life (Clark et al, 2014).

It is likely that many people in hospital will have palliative care needs, but research suggests that often their needs aren't identified (Gott et al, 2013). The National Survey of Bereaved People (VOICES) in 2013 in England found that quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home or in a hospice or care home (ONS, 2014).

More must be done to ensure people with terminal illnesses still receive the holistic care they need if they have to go into hospital.

Care homes are another place where delivering high quality, person-centred palliative care would be valuable for residents. Proper guidance needs to be introduced, implemented and evaluated to ensure this is the case (SPPC, 2006; GAIN, 2013).

8. Expanding the research and knowledge base

We know there is only limited research about palliative care for some terminal conditions. We also know there is no way of assessing whether current estimates of the number of people receiving specialist and generalist palliative care reflect the correct balance.

More research is needed which looks at quality, outcomes and unmet need at a local and population level. Without robust data, it is impossible to know if our approach to care is working or to plan services to meet people's needs – now and in the future.

9. Recommendations

We have identified a number of recommendations which could make access to palliative care significantly more equitable for everyone who needs it, regardless of which condition they have.

“I think Mum was very fortunate in that when she moved into the palliative stage, in the nursing home, it was a really good experience. She had an end of life care plan, which covered things like having her favourite music on and that she would like to be treated with dignity and respect.”

Woman whose mother had Parkinson's disease

Recommendations for governments

- Commit to providing the resources required to ensure all those with a palliative care need can access palliative services, regardless of their condition. This commitment should recognise the growing need for palliative care services into the future.
- A mandatory requirement for everyone involved in the healthcare of people with a terminal illness to undertake practice based palliative care training as part of their continuing professional development.

Recommendations for health and social care professionals

- Carry out regular holistic needs assessments for all people living with terminal conditions and, where it is in the best interests of the patient, introduce a palliative care approach or make referrals to specialist palliative care based on this assessment.
- Facilitate well-coordinated care by developing stronger relationships between condition-specific health professionals and palliative care specialists in both acute and community care settings.

Recommendations for health and social care bodies

- All health bodies should recognise in their planning (service, financial and workforce) the importance of ensuring that everyone understands what palliative care is, what it can offer patients across all disease conditions and how it can be accessed.
- Develop clear care pathways and guidance which can be used in service planning and commissioning, depending on the healthcare system.

This guidance should recognise the triggers identified by the research reviewed in this report. Where this already exists it should be reviewed against best practice and greater efforts should be made to encourage awareness and implementation.

- Health bodies should ensure their palliative care strategies and service delivery plans recognise the important role that can be played by disease specific nurse specialists. These should include what steps will be taken to ensure these nurse specialists receive training and support to enable them to deliver palliative care.

Recommended research priorities:

- The conclusions and recommendations above are only possible due to the research that has been undertaken. More research focusing on need and outcomes is essential.
- Develop a robust population-level assessment of need (including unmet need) for specialist and generalist palliative care in all UK nations.
- Develop quality and outcome indicators which focus on palliative care for people for whom palliative care would be beneficial across all disease conditions.

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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.

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