

# Triggers for palliative care

Improving access to care for people  
with diseases other than cancer

Implications for England

June 2015



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Care and support  
through terminal illness

# Introduction

*Marie Curie offers expert care, guidance and support to people living with any terminal illness, and their families. We also campaign to ensure everyone can access high-quality care, regardless of their personal circumstances, where they live or the conditions that they experience.*

In England, an estimated 355,000 of the 470,000 people who die each year need some palliative care.<sup>1</sup> Yet recent research, carried out by the London School of Economics and Political Science (LSE) and commissioned by Marie Curie, suggests that nearly 92,000 people who need palliative care in England each year are not accessing it.<sup>2</sup> With the number of people dying in England due to increase by 21% over the next 25 years,<sup>3</sup> this problem will get worse unless we act now.

It is an issue that will affect many of us at some time during our lives, whether we are caring for a loved one or need care ourselves in the future.

## **What do we mean by terminal illness?**

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.

A palliative approach is often recommended for people living with a terminal illness. Palliative care includes pain and symptom management, as well as physical, emotional and spiritual support. It has been proven to benefit people with many different illnesses including dementia, motor neurone disease, multiple sclerosis and chronic obstructive pulmonary disease.

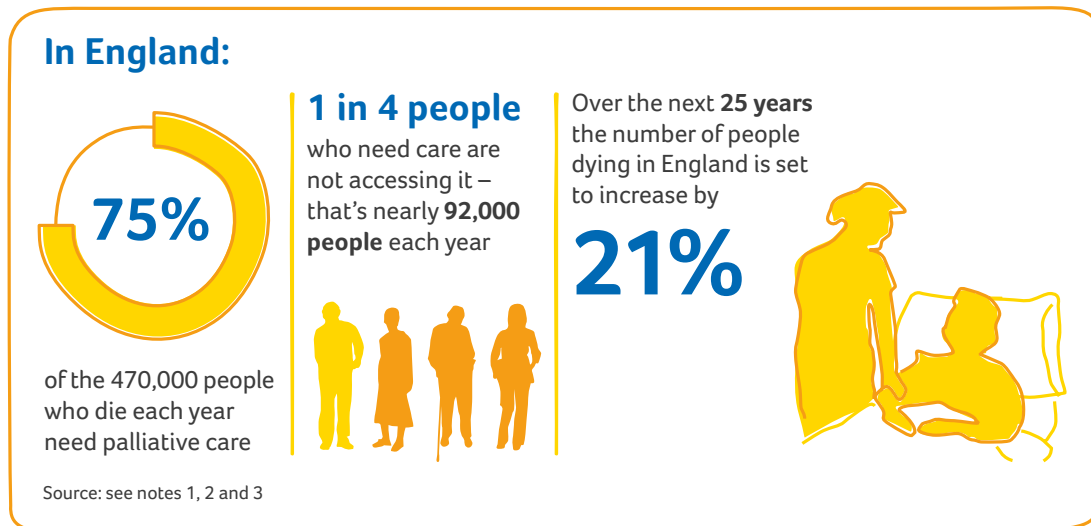
## **What do we know about palliative and end of life care for people with different conditions?**

There is significant anecdotal evidence which suggests those who have terminal conditions other than cancer are less likely to be offered or to access palliative care services. Part of the problem is that it's hard to find reliable data on who is affected due to under-reporting, under-diagnosis or late diagnosis.

In our report, *Triggers for palliative care*, we highlight evidence which shows the different experiences faced by people living with a terminal illness other than cancer. This document is a summary of these conditions and looks at who is

usually affected and the prevalence of each condition in England.

Read the full report at [mariecurie.org.uk/change](http://mariecurie.org.uk/change)



# The picture in England

*Access to high-quality palliative care is affected by the condition a person has. This section looks at the prevalence of terminal conditions other than cancer in England and how the health services are responding.*

## **What are multimorbidities?**

Throughout the UK, demographic changes mean that many more people are living with complex needs and multiple conditions.<sup>4</sup> Multimorbidity, defined as the co-existence of two or more long-term conditions in a person, is rapidly becoming the norm and this is set to increase as the population ages.<sup>5</sup> This means that people who are living with a terminal illness will often have a number of conditions to manage at the same time, such as cancer, chronic heart disease and stroke, especially if they are older. Evidence suggests that 44% of adults in the last year of life have multiple long-term conditions.<sup>6</sup>

People with multimorbidities often experience poorer health outcomes than those with single chronic conditions. They are more likely to die prematurely, be admitted to hospital and have longer hospital stays.<sup>7</sup> They are also more likely to have a poorer quality of life, experience depression and to have to negotiate fragmented services that focus on treatment and management of single conditions. People often have to cope with their conditions through complex self-management.<sup>8</sup>

This is further compounded by factors such as deprivation, with multimorbidity showing 10–15 years earlier in people living in the most deprived areas compared with those living in the least deprived areas.<sup>9</sup>

There is a clear need for integrated care across conditions, across primary and secondary care, between health and social care, and between medical care and self-management.

## **Heart failure**

Heart failure occurs when the heart fails to pump blood around the body at the right pressure.<sup>10</sup> The commonest causes of heart failure in the western world are coronary heart disease (CHD) and hypertension. Death can occur within a few weeks of diagnosis, but some people can live for 10 or more years. They may die suddenly and unpredictably at any stage during the course of the disease.

There were 86,766 deaths in England in 2012 where the underlying cause of death was listed as a type of heart disease.<sup>11</sup> There were 1.87 million people on the coronary heart disease register (around 3.3% of the whole population) in 2012 and 7.66 million people on the hypertension register

(around 13.7% of the population).<sup>12</sup> In 2013, the UK Government published the *Cardiovascular Disease Outcomes Strategy*, which estimated that in 2011 78,000 people died from coronary heart disease.<sup>13</sup> The strategy identified that patients with cardiovascular disease often received suboptimal care and were unable to die in their place of choice.<sup>14</sup>

### **Chronic obstructive pulmonary disease**

Chronic obstructive pulmonary disease (COPD) is a collective name for lung diseases that involve chronic airflow obstruction. These include chronic bronchitis, emphysema and chronic obstructive airways disease. Symptoms include breathlessness, cough and phlegm (caused by inflammation and subsequent thickening of the airways and increased mucus production), and decreased elasticity of the lungs. Damage done to the lungs is irreversible. Treatment usually involves relieving the symptoms with inhalers and advising on lifestyle changes, and is mostly offered by GP practices.<sup>15</sup>

COPD is typically under-diagnosed, with diagnoses often not occurring until the moderate to severe stages of the disease. As such, there are no accurate figures for how many people are affected by the illness in England. The British Lung Foundation estimates that 30,000 people in the UK die from the condition every year and that around three million people have the condition, but two million have not yet been diagnosed.<sup>16</sup>

### **Dementia**

The term 'dementia' is used to describe a range of conditions which cause damage to the brain, which tends to affect cognitive skills such as memory. The most common cause of dementia is Alzheimer's disease, but other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.<sup>17</sup>

The Alzheimer's Society estimates there are around 720,250 people living with a form of dementia in England in 2015 and the number is expected to rise by 40% over the next 12 years.<sup>18</sup> The Alzheimer's Society estimates that around 60,000 deaths every year in the UK can be directly attributed to dementia.<sup>19</sup> The Office of National Statistics considers it to be the leading cause of death among women, with more than 12% of all deaths classified as either dementia or Alzheimer's disease.<sup>20</sup>

### **End stage liver disease**

End stage liver disease (ESLD) is also known as cirrhosis, which is the result of long-term and continuous damage to the liver. The damage causes scarring, which interferes with blood flow to the liver. This can cause it to stop functioning and can lead to liver failure.

It is estimated that around 4,000 people die in the UK every year of ESLD. As most people are unaware they have the condition until it becomes serious, it is difficult to estimate how many people have it. It is estimated that every year around 700 people have a liver transplant as a result of the condition.<sup>21</sup>

“Because there was hope of a transplant he didn’t think of himself as terminal...If we had had a care plan, then that would have made it more real. It would have been something to have had that option – to say: ‘If you get to this stage then what do you want? Do you want to die at home?’ But it was never discussed with us.”

Woman whose husband died of end stage liver disease

### Motor neurone disease

Motor neurone disease (MND) is a progressive disease that attacks the motor neurones, or nerves, in the brain and spinal cord. This means messages gradually stop reaching muscles, which leads to weakness and wasting. MND can affect how you walk, talk, eat, drink and breathe. However, not all symptoms necessarily happen to everyone and it is unlikely they will all develop at the same time, or in any specific order.<sup>19</sup>

MND is a relatively rare condition, with two in every 100,000 people developing it every year. It is estimated that there are around 5,000 people in the UK living with MND at any one time.<sup>23</sup> Life expectancy for most people with the condition is between two and five years and around half will die within 14 months of diagnosis.<sup>24</sup>

### Multiple sclerosis

Multiple sclerosis (MS) is a condition of the central nervous system. In MS, the coating around nerve fibres (called myelin) is damaged, causing a range of symptoms. These include physical

symptoms such as fatigue, balance and vision problems and the condition can also affect memory, thinking and emotions.

MS affects almost three times as many women as men and symptoms usually start in a person’s 20s and 30s.

The MS Society estimates there are 87,686 people living with MS in England and that 3,983 are diagnosed with the condition every year.<sup>25</sup> In 2013, 1,100 people in England and Wales were recorded as having MS as the primary cause of death,<sup>26</sup> but it is thought that this may not accurately reflect the number of people dying with the condition.

### Parkinson’s disease

Parkinson’s disease is a progressive neurological condition that affects motor and cognitive function. The main symptoms of Parkinson’s are tremor, rigidity and slowness of movement.<sup>27</sup>

Parkinson’s UK estimates that one in 500 people have Parkinson’s – around 107,000 people in England. In 2013, Parkinson’s was listed as a cause of death for around 4,500 people in England and Wales,<sup>28</sup> however it is possible that this does not accurately reflect the number of people dying with Parkinson’s who need care at the end of life. This is because Parkinson’s is not considered to be a life-shortening condition, although it can cause situations that may result in death (ie it can weaken the immune system, meaning people may contract conditions such as pneumonia, which is then listed as the cause of death).

## Stroke

Stroke is a common type of cerebrovascular disease where part of the brain is damaged by a lack of blood supply, which can either be from a blockage to blood vessels or bleeding in the brain.<sup>29</sup> While acute stroke is not necessarily a terminal condition, some people with it may benefit from palliative care. The Department of Health's National Stroke Strategy published in 2007 called for people who had had a severe stroke and were not expected to recover to receive active end of life care.<sup>30</sup>

In England, more than 100,000 people have a stroke every year<sup>31</sup> and it is estimated that more than 45,000 people who have had a stroke die each year.<sup>32</sup>

“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

## Key issues

The evidence discussed in our report *Triggers for palliative care* brings to light a number of key issues which could be preventing people with conditions other than cancer accessing the care they need. These include:

- Prognostic uncertainty and hard to predict disease trajectories.
- A failure or reluctance to identify certain conditions (eg dementia and Parkinson's) as terminal by professionals.
- A lack of understanding of what palliative care is and what it can achieve for people with conditions other than cancer by both professionals and people with a terminal illness and their families.
- For some conditions, such as COPD, a paucity of research which demonstrates potential benefits of palliative care on patients' health outcomes (compared to the amount of research on lung cancer, for example).
- A lack of confidence from professionals in delivering care appropriate for people approaching the end of their life, for example, thinking that initiating end of life care discussions is someone else's role or concerns about the legal standing of advance decisions.
- Under-developed links between condition specialists and palliative care specialists.

## Triggers for palliative care

It is possible to identify a number of 'triggers' to palliative care which could provide effective indicators that someone with a terminal illness would benefit from palliative care services.

These include:

- Complex or persistent problems with symptoms, such as:
  - intractable pain
  - difficult breathlessness
  - nausea
  - vomiting
  - mouth problems
  - difficulty sleeping and fatigue
  - psychological issues, such as depression and anxiety
- High levels of hospital use, especially unplanned admissions.
- More than one condition (multimorbidities).
- Factors relating to nourishment and eating habits in people with cognitive impairment (eg dementia).
- The introduction of new interventions (eg gastrostomy feeding or ventilator support).
- For some conditions, such as MND, at the point of diagnosis.
- When a screening tool indicates that it would be appropriate (eg the Sheffield Profile for Assessment and Referral to Care (SPARC) or the Supportive and Palliative Care Indicators tool (SPICT)).

The research also highlighted some examples of good practice which help to evidence the real benefits that timely access to appropriate palliative care can have for people with different conditions. The following section considers what needs to change to ensure that good practice becomes the norm and all people with a terminal illness who need palliative care are able to access it.



# Redressing the balance

*We need everyone to play a part in breaking down the barriers identified in the research.*

A wide range of partners must work together to bring about and guide the necessary change: governments and those with responsibility for planning and commissioning services, health and social care professionals, voluntary sector organisations and, of course, people living with terminal conditions and their families and carers.

To break down these barriers, we need to:

- understand the right triggers to ensure timely referral
- change perceptions of palliative and hospice care
- achieve appropriate referral practices
- make palliative care everyone's business
- ensure better coordination and team working
- highlight the important role of nurse specialists
- improve palliative care across all settings
- expand the research and knowledge base

important issues about choice at the end of life and the fact that many people do not get their preference to die at home. However, it is important to note that for many people with these conditions, the fact is they are less likely to receive any care at the end of life, much less any choice about the care they receive.

## Considerations for England

In the run-up to the 2015 general election, the Health Select Committee published a report into end of life care<sup>33</sup> and the government commissioned an independent review into choice at the end of life.<sup>34</sup> Both reports raised

# Recommendations

*We have identified a number of recommendations which could significantly improve the equitable access to palliative care for everyone who needs it in England, regardless of which condition they have.*

The new Government must commit to providing the resources required to ensure all those who need palliative care can access palliative services, regardless of their diagnosis. This commitment should recognise the growing need for palliative care services into the future. Given the changes to health and social care structures in England following the 2012 Health and Social Care Act, which created new bodies including Clinical Commissioning Groups (CCGs), NHS England and Health Education England, it is vital that the different bodies work together to ensure these improvements take place. Adequate resources for supporting all those who need palliative care should be fully outlined alongside any plans for action.

*“It was a difficult illness to nurse. I felt almost abandoned until Marie Curie came along and I saw what real care was all about...Marie Curie asked for two case conferences to be held. No one had done that before. They wanted a plan of action for my wife. They got everyone involved in her care together.”*

Man whose wife died of motor neurone disease

Specific recommendations for action are set out below:

## **Change and improvement**

NHS England should:

- Require all CCGs to have in place a palliative care strategy that responds to the needs of their local communities and addresses access to palliative care for people with all terminal illnesses.
- Help build stronger relationships between condition-specific health professionals and palliative care specialists in both acute and community care settings. This should include a focus on improving referrals from condition-specific specialists to palliative care providers.

## **Education**

Health Education England should work with Skills for Care and the professional bodies to:

- Develop a mandatory requirement for everyone involved in the health and social care of people with a terminal illness (particularly generalists) to undertake practice based palliative care training as part of their continuing professional development.

## Leadership

NHS England should:

- Develop clear care pathways and guidance which can be used by CCGs 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.

## Local implementation

All CCGs must:

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

## Evidence base

The conclusions and recommendations above are only possible due to the research that has been undertaken.

The Government should recognise that palliative care research is underfunded and that poor data collection hampers the development of new ways of working.

The Government should:

- Commit to undertaking a robust population-level assessment of the need (including unmet need) for specialist and generalist palliative care in England.
- Ensure that this data is used to by commissioners, providers and health and social care professionals to reduce the number of people missing out on palliative care.

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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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