

# Triggers for palliative care

Improving access to care for people  
with diseases other than cancer

Implications for Scotland

June 2015



**Marie  
Curie**

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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 Scotland, it is estimated that around 40,000 of the 54,700 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 11,000 people who need palliative care in Scotland each year are not accessing it.<sup>2</sup> With the number of people dying in Scotland due to increase by 13% 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?**

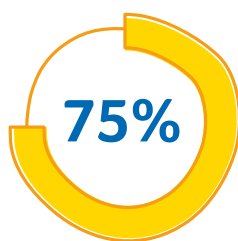
There is significant anecdotal evidence which suggests those who have terminal conditions other than cancer are less likely to be offered or to access palliative care services. Part of the problem is that it's hard to find reliable data on who is affected through under-reporting, under-diagnosis or late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

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

### In Scotland:



of the 54,700 people who die each year need palliative care

Source: see notes 1, 2 and 3

### 1 in 4 people

who need care are not accessing it – that's nearly **11,000 people** each year



Over the next **25 years** the number of people dying in Scotland is set to increase by

**13%**



# The picture in Scotland

*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 Scotland 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 is a chronic progressive condition resulting from weakness of the heart muscle. The most common 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 patients can live for ten or more years. They may die suddenly and unpredictably at any stage during the course of the disease.<sup>10</sup>

There were 7,239 deaths in Scotland in 2013 where CHD was the underlying cause. The Scottish Health Survey 2013 estimates that around 7.1% of men and 5.3% of women are living with CHD.<sup>11</sup>

In Scotland, there were 281 people with CHD per 100,000 population in 2013/14, a slight decrease since 2004/05.<sup>12</sup> There has been a general

increase in the number of people surviving 30 days following a first emergency admission to hospital. In the period 2004/05 to 2012/13, the percentage surviving 30 days rose from 82.5% to 87.2%. For those aged 75 and over, there is a similar pattern with 85.6% of people in this group surviving 30 days in 2013/14.<sup>13</sup> Last year, Scotland published its Heart Disease Improvement Plan, which included a commitment to develop a palliative care pathway for patients with heart failure.<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 Scotland. Practice Team Information estimates 105,000 patients were consulting a GP or practice-employed nurse for COPD in Scotland in 2012/13.<sup>16</sup> Far more patients consulted for COPD in the highest age groups compared to younger age groups.

### **Dementia**

The term 'dementia' is used for a syndrome associated with an on-going decline of the brain and its abilities. The most common type of dementia is Alzheimer's disease, but other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Most of the routine treatment is provided by GP practices.<sup>17</sup>

Practice Team Information estimates that primary care saw around 27,000 patients for dementia in 2012/13.<sup>18</sup> The estimated proportions of patients consulting for dementia were very low in the age groups up to and including 55-64 years and highest for those aged 75 years and over. In 2015, Alzheimer Scotland published information stating that 90,000 people have dementia in Scotland, with around 3,200 of these under the age of 65.<sup>19</sup>

### **End stage liver disease**

Chronic liver disease (CLD) refers to a range of conditions including end stage liver disease. It is characterised by scarring and destruction of the liver tissue. Early changes, such as 'fatty liver' (a build-up of fat in the liver cells) can progress via inflammation (hepatitis) and scarring (fibrosis) to irreversible damage (cirrhosis). Most chronic liver disease is symptomless or 'silent'. When symptoms do develop, they are often non-specific such as tiredness, weakness, loss of appetite and nausea. Causes of death from cirrhosis include development of liver failure, brain damage (encephalopathy), catastrophic internal bleeding (oesophageal varices) and also primary liver cancer.<sup>20</sup>

“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

There were around 16 chronic liver disease deaths per 100,000 population in Scotland in 2013, similar to the rate in 2012. In 2008, there were 1,059 CLD deaths in Scotland (692 in men and 367 in women). Between 2009 and 2013, CLD mortality rates have decreased across most age groups, with the highest mortality rates in people aged 60–64 years (43.6 per 100,000 population).<sup>21</sup>

### **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>22</sup>

In 2013, MND Scotland reported that 130 people in Scotland are diagnosed with MND each year, but because of its poor prognosis, fewer than 400 people have the illness at any one time. 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>23</sup>

### **Multiple sclerosis, Parkinson’s disease and acute stroke**

Multiple sclerosis, Parkinson’s disease and acute stroke are not typically thought of as being terminal and having one of these conditions might not affect someone’s life expectancy. However, for many who experience them, these conditions will eventually lead to their death.<sup>24</sup> A palliative care approach can improve the quality of life for people living with these conditions, perhaps alongside other active treatments.

### **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 were 11,119 people with MS in Scotland in 2012.<sup>25</sup> Data from the Scottish Public Health Observatory records 122 deaths in 2012 where the underlying cause of death was multiple sclerosis.<sup>26</sup> Data from routine statistics tends to underestimate the incidence and prevalence of MS and special surveys are likely to be more reliable. The estimates are affected by whether strict

or broad diagnostic criteria are used. There is also a lack of reliable national data on survival and mortality.

### 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>

In Scotland, there were between 120 and 230 people with Parkinson's disease per 100,000 population.<sup>28</sup> It is reported that the age-related incidence of Parkinson's disease means that the number of cases will increase by 25% to 30% over the next 25 years if the population of Scotland remains stable.<sup>29</sup>

### Acute stroke

Cerebrovascular disease (CVD) is largely a preventable disease. Stroke is one of the common types of CVD, occurring when the blood supply to part of the brain is interrupted and the brain cells are starved of oxygen.<sup>30</sup>

In 2013, there were 4,452 deaths in Scotland where CVD was the underlying cause. However, the number of new cases of CVD in Scotland has decreased over the last decade. The incidence rate of CVD in Scotland was 329 per 100,000 population in 2004/05 compared to 257 per 100,000 in 2013/14, a decrease of 21.8%.<sup>31</sup> Treating and preventing stroke is a national clinical priority for Scotland (Better Heart Disease and Stroke Care Action Plan).<sup>32</sup>

### 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)).

“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

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

## Considerations for Scotland

Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland was published in 2008. It provides a focus and momentum to improve palliative and end of life care for everyone in Scotland, and

to encourage efficient collaborative practice across health care, social care and voluntary sectors.

The Scottish Government has committed to producing a new strategic framework for action on palliative and end of life care by the end of 2015. As part of its initial scope of activity five key themes were developed to structure the strategic framework for action.

These are:

1. What matters to me?
2. Change and improvement
3. Leadership (national and local)
4. Education
5. Evidence Base

This is an opportunity to set out an ambitious plan to ensure that everyone living with a terminal illness gets the care they need.

The integration of health and social care moved forward in Scotland in April 2015 with the creation of 32 Integrated Joint Boards. Palliative care has been designated as a function that must be integrated. Shona Robison MSP, Cabinet Secretary for Health, Wellbeing and Sport, stated that palliative care would be an "early priority" for the new boards in a Scottish Parliament debate on integration.<sup>33</sup>

Boards are currently developing their strategies ahead of full implementation next April. As part of this process, they must address the issue of equal access to palliative care in all settings.

The Scottish Government has also committed to refreshing its 2020 vision document for health and social care in Scotland. The current edition does not include any reference to terminal illness, dying or death. As Scotland's guiding framework for health and wellbeing, it is essential this omission is addressed in the refreshed document.

These key policy developments present Scotland with an opportunity to shape care for people living with a terminal illness and their families for the next decade.

# Recommendations

*Our recommendations support the development of the proposed strategic framework for action in Scotland.*

The Scottish Government should commit to providing the resources required to ensure all those with a palliative care need can access palliative services, regardless of their condition, by 2020. This commitment should recognise the growing need for palliative care services into the future. Resources for supporting all those with a palliative care need should be outlined alongside the new framework for action when published later this year.

Specific recommendations for the strategic framework for action are set out below.

“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

## Education

The framework should set out:

- A mandatory requirement for every person involved in the healthcare of people with a terminal illness to undertake practice-based palliative care training as part of their continuing professional development.

## Change and improvement

The framework should require health and social care professionals to:

- 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.
- Facilitate well-coordinated care by developing stronger relationships between condition-specific health professionals and palliative care specialists in both acute and community care settings.

## Leadership

The framework should guide all integrated health and social care boards to:

- 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.
- 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 framework should:

- Develop a robust population-level assessment of need (including unmet need) for specialist and generalist palliative care in Scotland.
- Set out a clear plan to build a robust evidence base in Scotland. It is essential that there is even more research which focuses on need and outcomes.
- Review the Healthcare Improvement Scotland (HIS) Palliative Care Indicators and set out a programme of measurement and improvement against these.

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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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