

# Triggers for palliative care

Improving access to care for people  
with diseases other than cancer

Implications for Northern Ireland

June 2015



**Marie  
Curie**

---

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 Northern Ireland, an estimated 11,300 of the 15,000 people who die each year need 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 3,000 people who need palliative care in Northern Ireland each year are not accessing it.<sup>2</sup> With the number of people dying in Northern Ireland due to increase by 28% by 2037<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.

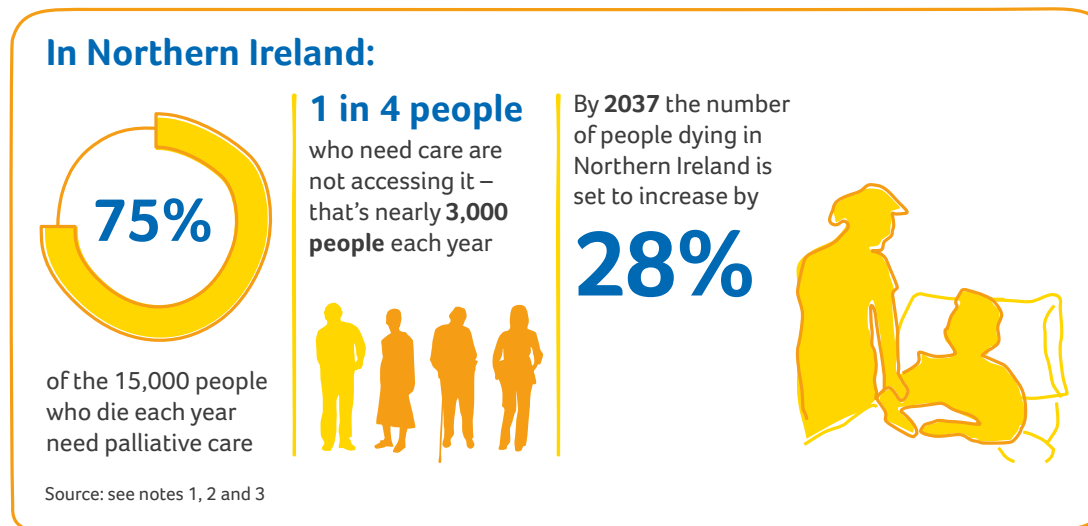
## **What do we know about palliative and end of life care for people with different conditions?**

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 Northern Ireland.

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



# The picture in Northern Ireland

*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 Northern Ireland 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 1,916 deaths in Northern Ireland in 2013 where CHD was the underlying cause. The Northern Ireland Chest, Heart and Stroke charity estimates that 74,500 people in

Northern Ireland (4% of the population) are living with CHD.<sup>11</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>12</sup>

COPD is typically under-diagnosed, with diagnoses often not occurring until the moderate to severe stages of the disease. We know that 28% of people die from respiratory conditions in Northern Ireland and figures from Northern Ireland Chest Heart and Stroke estimate there are currently 35,500 people in Northern Ireland (2% of the population) living with COPD.<sup>13</sup>

### **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.

There are approximately 20,000 people living with dementia in Northern

Ireland. We know that the vast majority of people living with dementia are over 65 and it predominately affects women. In 2013, 954 women and 451 men in Northern Ireland had their death attributed to dementia or Alzheimer's.<sup>14</sup> We know this figure is set to rise because Northern Ireland has a rapidly ageing population. It is estimated that the number of people diagnosed with dementia will rise to 60,000 by 2051.<sup>15</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>16</sup>

According to the British Liver Trust, there has been an average of at least 235 deaths from liver disease each year in Northern Ireland.<sup>17</sup> Official statistics in Northern Ireland show an increase of 39% in chronic liver disease deaths from 2001 to 2012, with the majority of deaths in males and in the 50-54 age group.<sup>18</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>

According to the MND Association, the incidence of MND in Northern Ireland is around two cases per 100,000 people per year.<sup>20</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>21</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>22</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.

It is difficult to obtain data on MS diagnoses in Northern Ireland. The MS Society estimates that there were 3,188 people living with MS in Northern Ireland in 2012<sup>23</sup> but according to a recently-answered NI Assembly question to the Department of Health, as of February 2015 there were only 1,555 people receiving treatment for MS. This highlights a potential unmet need of almost 50% of people with MS who need care. Official statistics in Northern Ireland record 48 deaths from MS in 2012, with the majority of people aged 55–59.<sup>24</sup>

### **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>25</sup>

Parkinson’s UK estimates that there are more than 3,000 people in Northern

Ireland living with Parkinson's disease of whom 15% will need palliative care.<sup>26,27</sup> There were 130 deaths attributable to Parkinson's in Northern Ireland in 2012, with the majority of people aged between 80 and 84.<sup>28</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>29</sup>

The Stroke Association reports that 4,416 people in Northern Ireland suffered a stroke in 2013/14 and, in the same year, 1,072 people died of the condition.<sup>30</sup> Of those affected by stroke, it is estimated around one third will make a full recovery and another third will die within the first month. The final third will have a substantial disability, and to varying extents, be dependent on others for help with everyday activities for the rest of their lives. Northern Ireland's regional stroke strategy, *Improving Stroke Services in Northern Ireland* (2008), has highlighted standards for stroke services and included provision for palliative care.<sup>31</sup> In its Review of Stroke Services (December 2014) Northern Ireland's Regulation and Quality Improvement Authority estimates that around 2% of the population are living with the symptoms of stroke or transient ischaemic attack. It has made 22 recommendations for improvements in stroke services in Northern Ireland.<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 Northern Ireland

*Living Matters, Dying Matters* (LMDM), the palliative and end of life care strategy for adults in Northern Ireland, was published in 2010. It set out a vision for palliative and end of life

care across all conditions and care settings in the region and made 25 recommendations.<sup>33</sup> The LMDM strategy runs from 2010 to 2015 and a successive palliative care strategy for Northern Ireland has not yet been announced.

The 2011 review of health and social care in Northern Ireland, *Transforming Your Care* (TYC),<sup>34</sup> also proposed six specific recommendations for the provision of palliative and end of life care:

- Development of a palliative and end of life care register to enable prompt transfer of information required by those providing palliative and end of life care.
- Enhanced support to the nursing home sector for end of life care.
- Individual assessment, planning, delivery and coordination of end of life care needs by a key worker.
- Electronic patient records in place for palliative patients, their families and staff.
- Targets to reduce the level of inappropriate hospital admissions for people in the dying phase of their terminal illness.
- Palliative and end of life care for children considered as part of the proposed review of paediatric services as referenced in the maternity and child health section.

A number of initiatives have made progress towards achieving objectives under these strategies. The Transforming Your Palliative and End of Life Care (TYPEOLC) programme is a joint initiative between Marie Curie and the Health and Social Care Board. This seeks to improve the design and delivery of coordinated services across Northern Ireland to enable people with palliative and end of life care needs to have choice in how and where their care is provided. Integrated Care Partnerships, consisting of collaborative networks of local care providers, have also been established under Transforming Your Care. These design and coordinate health and social care services under the clinical priorities of frail-elderly, respiratory, diabetes, stroke and end of life care.

There has also been scrutiny of progress under these initiatives. A review of the implementation of LMDM is currently underway by the Regulation and Quality Improvement Authority (RQIA). At the same time, Professor Sir Liam Donaldson has published the findings of his review of the health and social care system in Northern Ireland in a report entitled *The Right Time, The Right Place*.<sup>35</sup> The findings of these reviews present an opportunity to revisit and improve existing services, as well as identify and implement new initiatives to address unmet need and any shortfalls.

Despite progress made in the provision of palliative care across Northern Ireland, there is still unmet need for people with terminal illnesses other than cancer accessing palliative care.

The expiration of LMDM and the findings from the above reviews offer a unique opportunity for Northern Ireland to use past learning to shape care for people living with a terminal illness and their families into the future.

# Recommendations

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

## For the Northern Ireland Executive

- The Department of Health, Social Services and Public Safety and the Northern Ireland Executive should commit to providing the resources required to ensure all those who need palliative care in Northern Ireland can access palliative services, regardless of their condition. This should recognise the growing need for palliative care services into the future, taking into consideration Northern Ireland's rapidly ageing population.
- The future palliative care strategy (replacing LMDM) should outline resources for supporting all those who need palliative care, addressing care for people with all terminal illnesses in Northern Ireland.

- 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.

## 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 interest 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.

“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

## For health and social care bodies

- All health and social care 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. This guidance should recognise the triggers identified 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 and social care 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.

### **For researchers**

The conclusions and recommendations above are only possible due to research. It is essential that there is even more research which focuses on need and outcomes.

- Develop a robust population-level assessment of need (including unmet need) for specialist and generalist palliative care in Northern Ireland.
- Develop standard quality and outcome indicators which focus on palliative care for people for whom it would be beneficial across all disease conditions, and which translate across care settings.

# References

- 1 Hughes-Hallet T, Craft A, Davies C (2011). *Palliative care funding review: funding the right care and support for everyone*, Department of Health, London.
- 2 Dixon J, King D, Matosevic T et al (2015). *Equity in Provision of Palliative Care in the UK*. LSE, PSSRU, Marie Curie.
- 3 Office for National Statistics (2014). 2012-based National Population Projections.
- 4 Dixon J, King D, Matosevic T et al. (2015). *Equity in Provision of Palliative Care in the UK*. LSE, PSSRU, Marie Curie.
- 5 Fortin M, Soubhi H, Hudon C, Bayliss EA, van den Akker M (2007). *Multimorbidity's many challenges*. BMJ; 334(7602):1016-7.
- 6 Marie Curie (2015). *Changing the conversation: Care and support for people with a terminal illness now and in the future*.
- 7 Smith SM, Soubhi H, Fortin M, Hudon C, O'Dowd T (2012). *Managing patients with multimorbidity: systematic review of interventions in primary care and community settings*. BMJ; 345:e5205.
- 8 Health and Social Care Alliance Scotland (2014). *Many conditions, One life: Living well with multiple conditions*.
- 9 Smith SM, Soubhi H, Fortin M, Hudon C, O'Dowd T (2012). *Managing patients with multimorbidity: systematic review of interventions in primary care and community settings*. BMJ; 345:e5205.
- 10 Scottish Partnership for Palliative Care (2008). *Living and dying with heart failure: a palliative approach*.
- 11 Northern Ireland Chest, Heart and Stroke. *Statistics about chest, heart and stroke conditions*.
- 12 ISD Scotland, NHS National Services Scotland. *Chronic obstructive pulmonary disease*.
- 13 Northern Ireland Chest, Heart and Stroke. *Statistics about chest, heart and stroke conditions*.
- 14 Marie Curie and Alzheimer's Society (2015). *Living and dying with dementia in Northern Ireland*.
- 15 Department of Health, Social Services and Public Safety (DHSSPS) (2011). *Improving dementia services in Northern Ireland: a regional strategy*.
- 16 Scottish Public Health Observatory. *Definition of chronic liver disease*.
- 17 British Liver Trust (2014). *Early liver tests could save hundreds of lives in Northern Ireland*.
- 18 Northern Ireland Statistics and Research Agency (NISRA). *Register of deaths*.
- 19 MNDA. *About motor neurone disease*.
- 20 MNDA. *Statistics of MND*.
- 21 MND Scotland. *Time to benefit people with MND: MND Scotland Welfare Reform Campaign*.
- 22 For example, for people with MS: Koch-Henriksen N, Brønnum-Hansen H, Stenager E (1998) *Underlying cause of death in Danish patients with multiple sclerosis: results from the Danish Multiple Sclerosis Registry*. Journal of Neurology, Neurosurgery & Psychiatry, 65:56-59; people with Parkinson's disease: Mylne AQN, Griffiths C, Rooney C, Doyle P (2009) *Trends in Parkinson's disease related mortality in England and Wales, 1993-2006*. European Journal of Neurology, 16: 1010-1016; and for people who experience acute stroke: Stroke Association (2015) *State of the Nation: Stroke statistics*.
- 23 MS Society. *MS in the UK*.
- 24 NISRA. *Register of deaths*.
- 25 Parkinson's UK. *What is Parkinson's?*
- 26 Parkinson's UK. *Parkinson's nurses: affordable, local, accessible and expert care*.
- 27 UK Parkinson's Excellence Network. *Influencing planning to improve the quality of Parkinson's care in Northern Ireland*.
- 28 Parkinson's UK. *Parkinson's nurses: affordable, local, accessible and expert care*.
- 29 ISD Scotland, NHS National Services Scotland. *Stroke statistics update year ending 31 March 2014*.
- 30 Stroke Association. *State of the Nation: Stroke statistics*.
- 31 DHSSPS (November 2007). *Stroke Strategy Consultation document*.
- 32 The Regulation and Quality Improvement Authority (2014). *Review of stroke services in Northern Ireland*.
- 33 DHSSPS (2010). *Living matters, dying matters. A palliative and end of life care strategy for adults in Northern Ireland*.
- 34 *Transforming your care: a review of health and social care in Northern Ireland*.
- 35 DHSSPS (2014). *The right time, the right place*.

**Joan McEwan, Head of Policy & Public Affairs, Northern Ireland**  
**028 9088 2006**  
**joan.mcewan@mariecurie.org.uk**

**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](http://mariecurie.org.uk)**

 **MarieCurieUK**

 **@mariecurieuk**



---

**Care and support  
through terminal illness**