

Triggers for palliative care

Improving access to care for people
with diseases other than cancer

Implications for Wales

June 2015



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 Wales, an estimated 24,000 of the 32,000 people who die each year need some form of palliative care.¹ Yet recent research, carried out by the London School of Economics and Political Science (LSE) and commissioned by Marie Curie, suggests that nearly 6,200 people who need palliative care in Wales each year are not accessing it.² With the number of people dying in Wales due to increase by 9% over the next 25 years, this problem will get worse unless we act now.³

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 that those who have terminal conditions other than cancer are less likely to be offered or to access palliative care services. Data on hospital-based specialist palliative care in Wales shows a considerable gap in access for people who die from cancer (46%) compared to people who die from other conditions (5%).⁴ 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, an overview of

prevalence and an indication of current strategies for providing appropriate care for each condition in Wales.

Read the full report at mariecurie.org.uk/change.

In Wales:



of the 32,000 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 **6,200 people** each year.



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

9%



The picture in Wales

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 Wales 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.⁵ 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.⁶ 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.⁷

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.⁸ 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.⁹

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.¹⁰

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.¹¹

In 2012, CHD was responsible for more than 4,300 deaths in Wales, around 14% of all deaths.¹² Data from Quality and Outcomes Framework disease registers shows that in Wales in 2013-14, 122,688 people were living with CHD, 30,187 were living with heart failure and 7,056 with heart failure from left ventricular dysfunction.¹³

The Welsh Government published its Heart Disease Delivery Plan in 2013.¹⁴ This prioritises the effective transition to appropriate palliative and end of life care for all patients who need it. However there are no assurance measures to track whether this priority is being met and it is not reported on in the Heart Disease Delivery Plan Annual Report 2014.¹⁵

In May 2010, the Cardiac Networks Co-ordinating Group published symptom control guidelines and criteria for referring patients with end stage heart failure to specialist palliative care, to be used by health professionals caring for these patients.¹⁶

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.¹⁷

COPD is typically under-diagnosed, with diagnosis often not occurring until the moderate to severe stages of the disease. Data from the Quality and Outcomes Framework for 2013-14 found that 68,419 people in Wales were included on the COPD

register.¹⁸ Around 1,500 people in Wales die from COPD each year, which equates to around one in 20 deaths.¹⁹

The Welsh Government published its Respiratory Health Delivery Plan in 2014.²⁰ This acknowledges that palliative care improves the quality of life of people with advanced COPD. It tasks Local Health Boards to:

“Ensure adequate and equitable access to palliative care services, including respite care, for patients with respiratory disease in the endstages [sic] of their illness.”²¹

The percentage of patients with advanced and optimally treated respiratory disease receiving appropriate palliative and end of life care is included as a key assurance measure.

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.²²

Alzheimer’s Society estimates that 45,000 Welsh residents have dementia,²³ of whom 95% are aged 65 years and over. Around 2,500 people under the age of 65 in Wales have dementia. The latest data suggests that dementia is now the biggest single cause of death among women in England and Wales, having surpassed different forms of cancer for the first time.²⁴ By 2021, the number of people with dementia across Wales is projected

to increase by 31% and by as much as 44% in some rural areas.²⁵

As a recent report by Marie Curie and Alzheimer’s Society found, there is little strategic focus in Wales on the final stages of dementia.²⁶ The National Dementia Vision²⁷ includes no reference to the end of life care needs of people with dementia. Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales, through which much of the Welsh Government’s approach to dementia is focused, makes only a general commitment to “supporting the optimum state of wellbeing right through to the end of life for older people and those with dementia.”²⁸

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

“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

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.²⁹

In Wales, in contrast to almost all other major causes of death, the standardised mortality rate from liver disease for those aged under 65 has increased since 2001.³⁰ Based on statistics for 2010-12, around 260 males and 170 females die from chronic liver disease in Wales each year.³¹ About three-quarters of these died from alcoholic liver disease.³²

In April 2015, the Welsh Government introduced its Liver Disease Delivery Plan for the NHS and its partners to 2020. The plan includes a priority action to “support the provision of palliative care services for patients with chronic liver failure”.³³

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.³⁴ Life expectancy for most people with the condition is between two and five years and around half will die within 14 months of diagnosis.³⁵

The MND Association estimates that 250 people in Wales are living with the disease.³⁶

In recent years, advances have been made in providing specialist palliative care for people with MND in Wales. For example, palliative care led multi-disciplinary teams (MDTs) and clinics in North Wales have been developed.³⁷ The Welsh Government introduced its Neurological Conditions Delivery Plan in 2014, which sets out that:

“People in the later stages of long-term neurological conditions are to receive access to coordinated, effective and compassionate palliative and end of life care when they need them to control symptoms, offer pain relief and meet their needs for personal, social, psychological and spiritual support.”³⁸

This would be applicable to people with MND, but also to people living with more long term neurological conditions such as Parkinson’s disease and multiple sclerosis (see below).

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.³⁹ 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 that there were 4,235 people with MS in Wales in 2012.⁴⁰

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.⁴¹

An inquiry by the All Party Parliamentary Group for Parkinson’s disease into access to health and social care services for people with the disease and their carers in England, Wales and Northern Ireland found:

“A range of evidence from carers, health care professionals and the PDNSA [Parkinson’s Disease Nurse Specialist Association] highlighted the importance of access to specialist palliative care services for people with Parkinson’s disease. A number of clinicians [...] emphasised the need for strong links between these

services and the Parkinson's disease multidisciplinary team."⁴²

The inquiry also found significant shortfalls in access to Parkinson's disease nurse specialists, particularly in Wales and in Northern Ireland.⁴³

Parkinson's UK provides an information booklet to help people with the disease and their carers think about their future health in advance and to discuss their wishes and preferences for the end of life.⁴⁴

It is estimated that around one in 500 people are affected by Parkinson's disease.⁴⁵ Most people with Parkinson's start to develop symptoms when they are over 50, although around one in 20 people with the condition first experience symptoms when they are under 40.

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.⁴⁶

Statistics from Stroke Association show that one in eight strokes are fatal within the first 30 days, and one in four strokes are fatal within a year.⁴⁷

There were over 7,200 incidences of stroke in Wales in 2013-14.⁴⁸ In 2012, CVD was listed as the underlying cause in over 2,300 deaths.⁴⁹ In 121 of these deaths, the person had received a palliative diagnosis or had been treated within the specialty of palliative medicine.

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 disease) 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, there is a scarceness 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
 - difficulty breathing
 - 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 discussed has 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 Wales

In 2013, the Welsh Government published its end of life care delivery plan for 2013-16.⁵⁰ The plan sets out a series of delivery aspirations for the NHS in Wales to achieve in partnership with

voluntary organisations so that people dying in Wales have access to high quality care, whatever their underlying disease or disability. Priority actions for 2013-16 are set out for Local Health Boards and NHS Trusts under the following themes:

- Supporting Living and Dying Well
- Detecting and Identifying Patients Early
- Delivering Fast Effective Care
- Reducing the Distress of Terminal Illness for Patients and their Families
- Improving Information
- Targeting Research

The plan requires each Local Health Board to produce a delivery plan which sets out how it will achieve these priorities. The Welsh Government provides an account of how palliative and end of life care services are developing nationally in its annual report. Local Health Boards also produce annual reports which measure local progress against a series of outcome indicators.

The annual reports provide an opportunity to showcase the new initiatives and examples of good practice which have developed in line with the Welsh Government's vision of better care for all. A commendable indication of the progress made is

the increase in numbers of people included on Primary Care Palliative Care Registers, which has risen from 3,721 in 2009-10 to 7,152 people in 2012-13.⁵¹

The movement towards a prudent healthcare system is also providing new opportunities to discuss what sort of care should be available to people as they reach the end of their lives. The prudent healthcare approach is based on the principles of co-production, effective use of skills and resources, doing no harm and taking an evidence-based approach to practice so that it will be sustainable in the future. The Health Minister, Professor Mark Drakeford AM, has made designing the prudent healthcare system to meet the needs of people moving toward the end of longer lives a priority for 2015.

However there is much work to be done if Wales is going to achieve its vision of access to high quality care for everyone who needs it, regardless of their underlying condition.

One of the biggest challenges is the lack of information about current and projected levels of unmet need for palliative and end of life care services. Patient surveys show that specialist palliative care is consistently rated very highly for those who receive it.⁵² However, far less is known about the experiences of the majority of people with a terminal illness who do not access specialist palliative care. The evidence suggests many of these people will have one of the conditions discussed in this report. Are their needs adequately met? Does the reality of their experiences match the aspirations set out in the various delivery plans?

We need to act now to make sure that everyone with a terminal illness gets the care and support they need, regardless of their underlying condition or diagnosis.

Recommendations

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

Recommendations for the Welsh Government

- 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 bodies

- Health boards 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. This guidance should recognise the triggers identified in this report. A good example of this is Hywel Dda University Health Board's Prognostic Indicator Guide and Communication Sheet, which is adapted from the Supportive and Palliative Care Indicators Toolkit (SPICT).⁵³ Where this already exists it should be reviewed against best practice and greater efforts should be made to encourage awareness and implementation.
- Health boards 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 nurse specialists receive training and support to enable them to deliver palliative care.

"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 had motor neurone disease

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.

Recommended research priorities

- Set out a clear plan to build a robust evidence base in Wales. 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 Wales.
- Develop quality and outcome indicators which focus on palliative care for people for whom it 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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