



Care and support
through terminal illness

Marie Curie Response

We need to talk about Palliative Care

Introduction

We welcome the opportunity to respond to the Health and Sport Committee's Inquiry into Palliative Care in Scotland. Marie Curie's vision is for a better life for people and their families living with a terminal illness. Our mission is to help people and their families living with a terminal illness make the most of the time they have together by delivering expert care, emotional support, research and guidance.

According to a report from the Economist Intelligence Unit¹, the UK is considered a world leader in supporting people living with a terminal illness. In terms of its hospice care network and statutory involvement in end-of-life care, the UK ranks top of 40 countries measured. Yet despite this level of quality, our research estimates that there are nearly 11,000 people in Scotland who would benefit from, but are not currently receiving, specialist or generalist palliative care². Marie Curie believes that this needs to change and that everyone who needs palliative care has the option to receive it.

Unmet need

Earlier this year, Marie Curie commissioned the Personal Social Services Research Unit at the London School of Economics and Political Science (LSE) to undertake a review of inequities in palliative care. This review found that who you are, where you live and the condition you have has a significant impact on where and how you are supported throughout the course of a terminal illness³. Our report, *Changing the Conversation*⁴ identifies a picture of unmet need highlighting a number of factors which make it harder for some people to access care.

Conditions

While cancer is often seen as synonymous with palliative care, a wide range of research suggests that those with terminal conditions other than cancer are significantly less likely to receive generalist palliative care from their existing health professionals. People with degenerative conditions such as dementia, chronic obstructive pulmonary disease (COPD) or heart failure, or conditions such as motor neurone disease (MND) or multiple sclerosis (MS) are much less likely to get the palliative care they need, compared to those with a terminal cancer. Research also shows that those with some cancers are also less likely to access palliative care.

¹ Economist Intelligence Unit (2010). *The quality of death: Ranking end-of-life care across the world*. The Economist, 14 July 2010.

² <http://www.pssru.ac.uk/archive/pdf/4962.pdf>

³ <http://www.pssru.ac.uk/archive/pdf/4962.pdf>

⁴ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/changing-the-conversation-report.pdf>

“Completely and absolutely different. Everything was offered to you (with cancer)...But nothing for this (Parkinson’s). Not as I’ve been offered.” [Person with Parkinson’s and cancer]⁵

We know that palliative care can significantly benefit people with a whole range of terminal conditions, and not just at the end of life. Our experiences show that once people are referred to Marie Curie services people receive equitable care regardless of their condition. The focus is on the individual person, their experiences of a particular terminal illness and their present needs.

However, not everyone who needs specialist services is consistently and equitably referred across different conditions. It is important to highlight that not everyone who requires palliative care will need specialist palliative care services. Specialist palliative care services manage more complex care problems that cannot be dealt with by generalist services. We need to make sure that people with all terminal illnesses have access to generalist palliative care when they need it and those that require specialist palliative care are referred to the right services at the right time. Research shows that people who do receive palliative care generally only get it in the last few weeks and months rather than from the point of need.

Our recently published *Triggers for Palliative Care*⁶ report identifies a number of reasons for this inequity of access including prognostic uncertainty, reluctance to identify some conditions as terminal, a lack of understanding around what palliative care is and can do, and under-developed links and confidence among health and social care professionals.

“I think it would have been better if my mother had been dying of cancer, it would have been a lot easier... She would have had more services and more sympathy... The problem with someone in end stage heart failure is that there is no end in sight and they’re dying over months and months.” [Daughter whose mother died of heart failure]⁷

Individual circumstances

Changing the Conversation also shows that factors completely unrelated to your illness can also affect how easy it is for you to get the care you need. Research⁸ shows that if you have a terminal illness, you may find it more difficult to access the right care if you are 85 years of age or over, are from a black, Asian or minority ethnic background and live in the most deprived or rural areas of the country.

“I didn’t belong in terms of what I felt like age-wise, disability-wise, because I was still walking - and so what I saw was lots of people in wheelchairs, lots of people over the age of 50 or 60 and I was 20-something. And also I didn’t see anybody from a different ethnicity, so it was predominantly white...male, 50s and 60s...in some ways I left feeling more isolated” [Terminally ill person with MS on a support group]⁹

⁵ Marie Curie Policy and Public Affairs (2014). *Difficult conversations with dying people and their families*. Marie Curie, March 2014 <http://blog.mariecurie.org.uk/wp-content/uploads/2014/03/S691-Difficult-Conversations-report.pdf>

⁶ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-full-report.pdf>

⁷ *ibid*

⁸ <http://www.pssru.ac.uk/archive/pdf/4962.pdf>

⁹ Marie Curie Policy and Public Affairs (2014). *Difficult conversations with dying people and their families*. Marie Curie, March 2014

We believe that palliative care should be consistently delivered across Scotland throughout public, independent and voluntary sector partners so a universal level of care and support can be provided, no matter who you are or where you live.

“My overwhelming impression is that there’s lack of consistency. It all depends where you live.” [Bereaved carer – daughter with cancer]¹⁰

We want a better life for people and their families living with a terminal illness. In order to do this we need to make sure that people get the care that they need when they need it, regardless of personal circumstances or condition.

Improvement

We would like to see a clear commitment and process to ensure that everyone with a palliative care need has access to it by 2020. We believe the answer to improving access to palliative and end of life care and making sure it is equitable and available in all areas and for all types of terminal illness, is threefold. We need to:

1. understand what palliative care looks like in Scotland
2. undertake targeted service provision improvement including education and training of health and social care professionals, and
3. challenging perceptions, including what people understand by the terms palliative care and terminal illness.

1. What does palliative care look like in Scotland? – the need for robust data

Scotland does not currently collect and analyse enough data to show the provision of palliative care across the country or the progress we are making in improving care for people living with a terminal illness. However, Scottish Government, NHS Boards, and other colleagues across a range of organisations recognise the need for a clear shared vision on the future of palliative and end of life care in Scotland¹¹.

We need to set out a clear plan to build a robust evidence base by collecting and analysing data against the indicators for palliative and end of life care and on patient and family experiences. This will help inform a robust population level assessment of need and unmet need for generalist and specialist care services. We hope that the new strategic framework for action on palliative and of life care, currently under development by Scottish Government, will build on this and embody that shared vision on future services. This should include an approach to respond to the views of people who use palliative care services, and link to a refreshed Scottish Government 2020 vision, the strategic vision for achieving sustainable quality in the delivery of healthcare services in Scotland.

In May 2015¹², the Minister for Sport, Health Improvement and Mental Health addressed the importance of being able to have data and information to be able to describe progress and improvement work. He noted that future plans include:

¹⁰ Marie Curie Policy and Public Affairs (2014). *Difficult conversations with dying people and their families*. Marie Curie, March 2014

¹¹ <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc>

¹² <http://www.scottish.parliament.uk/parliamentarybusiness/report.aspx?r=9942&mode=pdf>

- a national approach to measurement and monitoring, including a key indicator on end-of-life care as part of the requirements to measure improvements in health and wellbeing outcomes under health and social care integration
- encouraging the local use of the National Survey of the Bereaved (VOICES) survey to support improvement and provide data at a national level to inform future strategy and policy development, and
- working in partnership with the NHS, the Convention of Scottish Local Authorities and the third sector to develop a new framework to effectively listen and respond to the voices of those who use health and social care services.

We need to have an accurate picture to improve both access and improvement methodologies within existing services. We support the above commitments and are happy to support the Scottish Government in achieving these aims.

2. Targeted improvement - workforce, training and education

In our report, *Triggers for Palliative Care*, published in June 2015 we highlight evidence which shows a number of barriers people face in receiving palliative care. These include a lack of understanding about what palliative care is – by both the public and professionals, lack of recognition of a condition as terminal or when to introduce palliative care where a condition has an uncertain trajectory, a lack of confidence communicating with people as they approach the end of life and underdeveloped links between professionals who care for people with specific conditions and palliative care specialists.

“If you’re having a really busy night and you’re perhaps under pressure to be getting round and you, perhaps, anticipate that it (the call) might be lengthy, then maybe a ‘heart-sink moment’ ... I might briefly think ‘oh God, not a palliative’.” (GP)¹³

We often speak about postcode lotteries across Scotland in the equitable provision of access to health and social care services. While this can often be the case, we have found that a healthcare professional lottery also exists. The care that people receive often depends on who their healthcare professional is, how they work and their priorities. Some professionals do not have the time or training to engage with palliative care methods or see it as a priority area. This means that they do not engage in palliative care conversations with their patients or the existing professional infrastructure that supports, informs and communicates palliative care planning, preferences and care.

One of the main priorities in improving access to palliative care for people with all conditions across Scotland is to ensure that health professionals have access to mandatory generalist palliative care training and, importantly, see it as an integral part of their job. In particular, there also needs to be a focus on out-of-hours provision of palliative care. Often there is a lack of confidence and capacity to address palliative care needs out-of-hours which can lead to unnecessary admissions at a time that can be frightening for patients and families. This could be addressed by both mandatory training for medical staff and the streamlining of out-of-hours advice and signposting to palliative care. We believe palliative care should be part of core competencies in medical training, regularly updated, and encouraged and demonstrated by senior staff. It is crucial that this applies to all types of health and social care professionals, from GPs to cardiologists. As such it would be appropriate to include it in the national healthcare curriculum.

We know that having early conversations with people about their condition is key to helping them live as well as possible during their terminal illness. We believe that it is the responsibility of the professional who has identified that a person’s illness has become terminal to have that initial

¹³ Marie Curie Policy and Public Affairs (2014). *Difficult conversations with dying people and their families*. Marie Curie, March 2014

conversation. We believe it is reasonable to expect that people will have the opportunity to sit and talk about their condition, their future and what they can expect. This will be different things for different people. Often this generalist stage is missed and it is only later in the course of a person's illness that specialist palliative care services are called to speak with patients, but this can often be too late.

"I don't think they [the family] had a lot of preparation. It would have been nice for the doctor to have spoken to them because he was still having all of his treatment...so in a way that's hope for them that he might pull round. We knew that wasn't going to happen... but in that situation you can't say: 'All we want to do is keep him comfortable, because this is his last few days.' You can't say that because it's not really been broached." (Nurse)¹⁴

It is imperative that health and social care professionals have the right skills and support in place to have conversations around choices in palliative care and that these conversations can evolve over time. That way, even if someone may not require immediate palliative or end of life care, they know what to expect or who to contact for support in the future. This is especially important for people with conditions other than cancer, where there may be uncertainty on a person's prognosis or the trajectory of their condition. People need to be more aware of what their condition means and that conversation needs to be undertaken by people who are trained to do so.

This is also important in managing patient expectations. When we talk about patient choice in health and social care there is a tendency to assume that people can choose all aspects of their care. However, this is often not the case. Patient choice is only applicable within the context of a person's own circumstances and often, despite perceptions, when people access palliative care they do receive the best care that will work within their situation. We recommend that people's palliative care preferences are discussed in a more person-centred way, such as discussing what is important to them and what their goals are. This information will help to inform the care that they receive once recorded in their key information summary (KIS); an electronic information system managed by GPs that forms the centralised collection of information about a patient.

We believe that this can be addressed through education and training targeted at health and social care professionals, including:

- Improving palliative care across all settings – making sure staff, patients and their carers have enough information about palliative care and that this can be delivered by a wide range of professionals across a range of settings.
- Ensuring all medical and nursing staff, including those working in the community, know about their local specialist palliative care teams and how to contact them. This will involve targeted training, education and identification of appropriate referrals practices and referral criteria.
- Ensuring better coordination and team working - strong links and effective coordination with specialist palliative care teams can help clinical specialists ensure appropriate care for their patients.
- Recognition of and using the right triggers for palliative care can help health professionals identify when these needs might require a palliative care approach.
- Effective communication between care teams and at points of care transition including use of existing systems, such as the KIS, to communicate care and treatment wishes.

Effective communication

Communication is one of the most important aspects of ensuring people receive good palliative care. We have already highlighted the importance of good communication between professionals and

¹⁴ Marie Curie Policy and Public Affairs (2014). *Difficult conversations with dying people and their families*. Marie Curie, March 2014

patients, but how professionals communicate with each other is also vitally important. One of the biggest frustrations our staff experience is not being able to access or share information. This is partly due to differing IT systems used within primary and secondary care and within different providers, partly due to confidentiality and information governance considerations and partly again due to the healthcare professional lottery. For example, the key information summary (KIS) has been operational in Scotland for over a year, yet many professionals do not know what it is or how to use it effectively.

At Marie Curie, consultants will often spend over an hour getting to know new patients and as a result will have a wealth of information. However, they are unable to add this to the patient's KIS, which currently only GPs can add to or amend. In Scotland a number of different electronic systems are used to record patient information across public, independent and third sectors and between primary and secondary care. These do not automatically connect to the KIS and so when GPs receive information from consultants, they often have to re-enter it which can be time consuming and therefore not completed. We would like specialist palliative care professionals to be able to add information directly to the KIS. This will provide a significant opportunity to upload and keep advanced care planning up to date.

There are also system compatibility issues surrounding the use of Do Not Attempt Resuscitation (DNACPR) orders in end of life care. Conflicting electronic systems, and how data is reorganised within these systems, can lead to healthcare professionals being unclear on patient wishes. This is inadequate to support and communicate the complexity of people's care across different health and social care organisations. There needs to be mechanisms to consistently share information in a timely and accessible way, with an effective IT infrastructure to support it.

There also needs to be systems in place to recognise when people need palliative care early in their pathway. We support the Scottish Government's plan to review the Healthcare Improvement Scotland (HIS) Palliative Care Indicators and set out a programme of measurement and improvement against these. This should be alongside the promotion and use of screening tools, such as the:

- Scottish Patients at Risk of Readmission and Admission (SPARRA) tool to identify patients who may benefit from a more anticipatory approach to their care
- Supportive and Palliative Action Register (SPAR) to identify changing palliative care needs in the last months of life in frail elderly people and people with dementia, and
- Supportive and Palliative Care indicators Tool (SPICT) for identifying patients in primary and acute sectors where palliative care would be appropriate.

We would also recommend the adoption a standard definition for both palliative care and terminal illness across public, independent and voluntary sectors to enhance understanding and recognition. We have attached the Marie Curie definitions for these to contribute to the discussion.

3. Challenging perceptions

Our *Changing the Conversation* report accentuates the need to have a conversation about terminal illness and palliative care, to include people who have a terminal illness themselves or are supporting a loved one, health and social care professionals, service planners and policy makers.

We will all die; we need to think about what happens when we reach that point; we need to think about the lives that we want for ourselves and our families. And yet it's a conversation that many don't want to think about.

We need to reduce the awkwardness about talking about death and dying, to challenge public perceptions and understanding and to enable a more public debate of the issues. A number of

approaches should be considered, for example, school-level education or public health approaches to promote public openness around death, dying and loss to tackle the stigma that can surround these issues. For example, research exploring work between hospices and schools is currently being funded by Strathcarron Hospice in Stirlingshire¹⁵. There is also a considerable role for care in the community to address the stigma associated with death and dying, increase support and reinforce coping mechanisms for families and carers during a person's condition and after death. We recommend the establishment and real investment of a government-led public health campaign run through Good Life, Good Death, Good Grief initiative¹⁶.

However, even in health and social care there is a stigma attached to talking of death and dying. This is why we'd like the national conversation on the future of health and social care in Scotland, launched by the Cabinet Secretary for Health, Wellbeing and Sport in June 2015, and associated strategy that builds on the 2020 vision, to include references to terminal illness, palliative care, dying and death.

Many people with a terminal illness don't get the information and support that they need. They, and their families, often face uncertainty about their prognosis and what that means for their lives. Early conversations about palliative care which includes what that means for them, learning what their needs are and developing plans according to their preferences is crucial. Often the delivery of a terminal diagnosis is thought of as a rapidly approaching death sentence and palliative care as something that only benefits people at the very end of life. While this can be the case, especially with traditional cancer-orientated notions of palliative care, it is not always true when it comes to other terminal illnesses. Some disease trajectories are hard to predict and people can live for many years accessing generalist and specialist palliative care when needed. Palliative care can be about improving quality of life and continuing to support people to live well through the course of their condition.

"I had a phone call, 'Oh by the way just to let you know you've got end stage COPD. We've written a letter to your social services so we sent you a copy so you'll find out, so we thought we'd better let you know by phone call'...I went into meltdown...I just sat in the sun lounge with the cats and cried my eyes out because end stage, I thought that was it, I was going to die tomorrow. Nobody had explained what actual end stage means." (Person with COPD)¹⁷

In May 2015, our Edinburgh Hospice held a consultation event on current and future Marie Curie services. The most important thing for patients and families was that services responded to the genuine choice of the families, that they had a named person for contact, that there is back up from specialists when needed, that clear information about their situation and support is given and assurance that respite care, even for a few hours, is of high quality.

We want to ensure that people receive consistent, timely and appropriate care and support across Scotland. This includes joined up working between health and social care services, primary and secondary care, and between public, private and voluntary sector partners. We believe that policy makers, health and social care professionals, service planners and communities must talk honestly about what sort of care and support we want to give people affected by terminal illness.

Palliative care has been designated as a function that must be integrated under the new Integrated Joint Boards. In March 2015¹⁸, Shona Robison, The Cabinet Secretary for Health, Wellbeing and Sport addressed the importance of palliative care in the integration of health and social care to provide more

¹⁵ <http://spcare.bmj.com/content/early/2013/02/22/bmjspcare-2012-000334.full>

¹⁶ <http://www.goodlifedeathgrief.org.uk/>

¹⁷ Marie Curie Policy and Public Affairs (2014). *Difficult conversations with dying people and their families*. Marie Curie, March 2014

¹⁸ <http://www.scottish.parliament.uk/parliamentarybusiness/report.aspx?r=9860&mode=pdf>

coherent services and stressed this should be an early priority for the new integrated boards. We welcome this commitment and are happy to support the Integrated Joint Boards to develop and achieve the vision of ensuring people have access to and receive palliative care at the right time.

Summary

Palliative care systems in Scotland are recognised as world class. However, we still fall short of ensuring that everyone who needs palliative care can access it in a form, time and place that they need. Often generalist palliative care skills are lacking in health and social care professionals, meaning that many of those people living with a terminal illness don't receive palliative care, or when they do, it is through last minute referrals to specialist services and it is too late to have a meaningful impact on their quality of life.

We believe that people living with a terminal illness deserve a good quality of life and we believe this can be achievable through palliative care. That's why we would like to see a clear commitment and process in place to ensure that everyone with a palliative care need has access to it by 2020.

The journey to achieve this commitment starts with the recommendations outlined within this submission. As a nation we need to understand what palliative care looks like in Scotland, to undertake targeted service provision improvement including education and training of health and social care professionals and upgrading the infrastructure to support this, and we need to challenge societal and cultural perceptions of death and dying.

Summary of recommendations

We want to make sure that everyone with a palliative care need has access to it by 2020. This includes making sure that:

1. all people living with a terminal illnesses receive generalist care when they need it, regardless of circumstances or condition, and
2. those who require specialist palliative care are referred to the right services at the right time.

To do this, we need to:

- understand what palliative care looks like in Scotland, including:
 - Setting out a clear plan to build a robust evidence base by collecting and analysing data against the indicators for palliative and end of life care and on patient and family experiences.
 - Developing a robust population level assessment of need and unmet need for generalist and specialist care services.
 - Developing of a clear shared vision on the future of palliative and end of life care and an approach to respond to the views and priorities of people who use palliative care services.
- undertake targeted service provision improvement including education and training of health and social care professionals, including:
 - Tackling the healthcare professional lottery by creating mandatory generalist practice-based palliative care training with updated continuing professional development and systems to ensure peer and senior staff support to enable professionals to identify when a palliative care approach is required.
 - Ensuring all health and social care professionals have the skills and support in place to have conversations about generalist palliative care.
 - Ensuring better knowledge, coordination and team working between health and social care

professionals and their local specialist palliative care teams, including how to contact them and information on referrals practices and criteria.

- Mechanisms to consistently recognise palliative care needs and share information including systems to increase use of, and engagement with, existing systems such as the key information summary (KIS). This should include investment in effective IT infrastructure to support this.
- challenge perceptions of palliative care and terminal illness, including:
 - Reducing the awkwardness about talking about death and dying using public health approaches, including establishment and real investment of a government-led public health campaign run through Good Life, Good Death, Good Grief.
 - Recognition of terminal illness, death and dying in the national conversation on health and social care and associated strategy that builds on the 2020 vision.
 - Palliative care as an early priority for joint integration boards.

Further information:

We are happy to provide further information to support this consultation. For more information, please contact:

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