



Enough for everyone

Challenging inequities in palliative care

Event report: 15 September 2016

1. Introduction

In 2015, research published by the London School of Economics (LSE) and commissioned by Marie Curie, highlighted that nearly 11,000 people who need palliative care in Scotland each year are not accessing it. That means that 1 in 4 people who die in Scotland miss out on the care they need¹.

The research highlighted a number of barriers as to why people might not access palliative care.

However, it also highlighted that certain other groups of people receive less palliative care than others with a comparable need. While not an exhaustive list, the research showed that the following people aren't usually accessing the care they need. These are people:

- who are over the age of 85
- from black, Asian and minority ethnic (BAME) backgrounds
- who identify as lesbian, gay, bisexual and transgender (LGBT)
- are from more deprived areas, and
- who are socially isolated or live alone.

We do not think this is good enough and needs to change.

1.1. Challenging inequities in palliative care

Following on from the publication of the LSE report, Marie Curie has continued to explore why certain groups of people miss out on palliative care. We have published a number of reports and commissioned research into these areas to try and ascertain the barriers and identify solutions.

On 15 September 2016 Marie Curie hosted a seminar in Edinburgh to further explore these issues. The purpose of the event was to explore, on a practical level, the challenges which these groups of people face accessing care at the end of life. We gathered experts from across the country to talk about the issues and seek solutions to ensure everyone gets the care they need. Over 70 people attended the seminar, including informal carers, MSPs, councillors, journalists, academics, civil servants, third sector representatives, health and social care practitioners and Marie Curie staff from different services.

The Scottish Government has recognised that things need to change and last year published a new Strategic Framework for Action on Palliative and End of Life Care. This set out a vision that by 2021, everyone who needs palliative care will have access to it, and ten commitments to make this vision a reality. Alongside this it has legislated for the integration of health and social care in Scotland which has seen the responsibility for palliative care move to the new health and social care partnerships.

Marie Curie will share this report with stakeholders, including the Scottish Government and the health and social care partnerships, to help inform ongoing work.

2. Exploring inequities



Photo 1: Speakers (from left to right): Maureen O'Neill, Sophie Bridger, Claire Stevens, Prof Scott A Murray, Christine Taylor, and Dr Emma Carduff.

2.1. Older people

Speaker – Professor Scott A Murray, University of Edinburgh

Professor Murray outlined findings from a new collaborative report from Marie Curie and the University of Edinburgh, *Why do older people get less palliative care than younger people?* The report shows that most people aged 70 and over in Scotland are missing out on palliative care. The link to the full report is in the links section below.

Older people receive disproportionately little specialist or generalist palliative care. Most old people will probably be getting some support and healthcare from a generalist service, but more could and should be done to support them when they get a serious illness or become very frail.

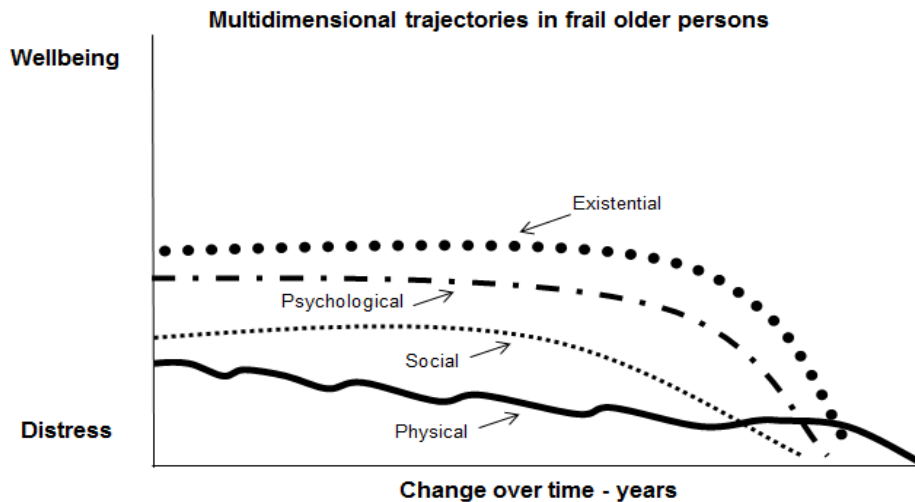
Scotland's population is ageing, the number of people aged 75 and over is projected to increase from 420,000 to 780,000 by 2037 (an 86% increaseⁱⁱ). This coupled with an increasing average life expectancy, means that people in Scotland are living with more complex needs than ever before. We need to make sure that older people get the care they need.

Barriers to accessing care can include that older people may think their illness is just them getting old. There are also factors around the under-reporting of serious illnesses and under-identification of older people for palliative care by healthcare professionals. The role of the geriatrician can also sometimes be unclear in palliative care.

This becomes more complex alongside issues of frailty. Identifying a frail older person for palliative care can be very challenging, as there are less clear early signs that they are in need. Frailty is not

a well-defined terminal illness with a clear beginning and distinct symptoms, but people still benefit from a palliative care approach as much as those with a clearly defined terminal illness.

Identifying frail older people for palliative care and support must consider the existential, psychosocial and spiritual decline as much as the physical decline.



Anna Lloyd PHD – Exploring the changing multidimensional experiences of frail older people towards the end of life, University of Edinburgh 2015

Psychosocial, existential and spiritual aspects may begin to deteriorate before someone's physical wellbeing. Support should be triggered at the beginning of decline in any of these dimensions of a person and not just the physical, as is currently more likely. Practitioners need to be able to identify when a non-physical decline might begin or has begun in a person in order to ensure that they receive the care they need.

Recommendations:

- More effort should be made to identify triggers for palliative care in older people, particularly those with frailty.
- Practitioners need training and support to identify loneliness, worries and emotional distress in older people and to respond with relevant responses, such as promoting resilience and social activities.
- Helping frail older people to request and receive the palliative care and support they need must be a part of a public health approach that allows people to live well and die well in due course.

2.2. Black, Asian and Minority Ethnic groups

Speaker – Christine Taylor, Greater Manchester and Eastern Cheshire Strategic Clinical Network

Research highlighted in the LSE report shows that some people from black, Asian and minority ethnic (BAME) backgrounds report poorer quality of care at end of life. They rate care from care homes particularly poorly and are more likely to die in hospital than a care home, compared to people of white ethnicity.

Most people from BAME communities, as with other communities, want to die at home. It can be very difficult to meet their wishes and needs in a hospital setting. Sometimes hospital settings and systems may be a barrier to this. For example, many people from BAME communities have large

families and social groups that extend into their neighbours, and all feel the need to be a part of care, yet hospitals limit the number of visitors at any one time. There are often limited facilities to support families, especially large families, outside of the wards.

The LSE study highlighted a range of barriers faced by BAME communities. These include lack of cultural and religious sensitivity in how services are delivered, discrimination (and/or fear of it), absence of translation resources, different cultural views regarding the acceptability of openly discussing death, shortages of female doctors for Muslim women and assumptions that family members from BAME backgrounds will be able and willing to care for relatives at home.

Christine Taylor from the Greater Manchester and Eastern Cheshire Strategic Clinical Network spoke on minority perspectives on end of life care. She presented the example of a project 'Through Our Eyes', where families from BAME communities who have experienced the death of a loved-one shared their stories to help improve end of life care in North West England. The project was aimed at raising awareness across the Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks (GMLSC SCNs) footprint around some of the end of life care issues and needs in BAME communities. In particular, those happening between families and care professionals, commissioners and providers and within communities to enable a more holistic palliative and end of life care to be delivered.

Christine highlighted that language barriers can make it difficult to have conversations around dying and death, but also when it comes to anticipatory care planning and DNACPR. There are limited resources available to support practitioners to have these conversations with people from BAME communities.

In Scotland, there is also evidence to show that many of those from Black, Asian and minority ethnic (BAME) communities in Scotland are not accessing palliative care and that palliative care is not necessarily sensitive to the different needs of minority ethnic groups in Scotland. There is a link to Marie Curie's report [Palliative and end of life care for Black, Asian and Minority Ethnic Groups in Scotland – Exploring the Barriers](#) at the end of this report.

Recommendations:

- Those planning, developing and commissioning services need to do more to identify and reflect the palliative and end of life care needs of BAME communities in their areas.
- We need to gather the experiences of communities and engage with them directly through consultation.
- There needs to be more training and support for those supporting people from BAME communities at the end of life.

2.3. Lesbian, Gay, Bisexual and Transgender (LGBT)

Speaker – Sophie Bridger, Stonewall Scotland

The LSE report found a significant lack of evidence about LGBT people's experiences of palliative and end of life care. In June 2016, Marie Curie published a report on the reality of end of life care for LGBT people, [Hiding who I am: The reality of end of life care for LGBT people](#). It identified a number of key issues experienced by LGBT people at the end of life. These include delayed or not accessing palliative care due to anticipated stigma or discrimination based on previous experiences, complexities of religion and LGBT end of life care, assumptions about identity and family structure, varied support networks, increased pressure on LGBT carers and unsupported grief and bereavement.

Sophie Bridger from Stonewall Scotland spoke further about the lack of research around access to and use of palliative care services by LGBT people and how they are often shaped by previous experiences and expectations of health and social care.

- One in six LGBT people are discriminated against in using public services – including palliative care.
- One in four LGBT people had heard health and social care staff use inappropriate language.
- Half of LGBT people expect to be discriminated against.

Older LGBT people have lots of negative experiences and expectations based on a life time of discrimination and bullying. Especially as many lived large parts of their lives where being LGBT was far less accepted than it is today. As a result of these experiences many LGBT people delay or deter access to health and social care services. Many are afraid of the discrimination or abuse that they might receive.

A person's sexuality plays a large part in any approach to person-centred care, as it involves partners, family members and friends. There are also legal and practical issues such as Next of Kin. However, there is a distinct lack of training and support to health and social care staff for supporting LGBT people and their needs, with three quarters of staff not getting the training that they need. Practitioners need to understand when things are and are not relevant. They need to know when and how to ask questions.

There can also be issues for LGBT people following the death of a loved one. For example, a partner may be completely left out if the deceased person had not come out to family. This can have a significant impact on the grief of the bereaved.

Recommendations:

- Staff need more training and education on the specific concerns or needs of LGBT people at the end of life, including in the context of home care services.
- Services need to challenge stereotypes, promote role models, share best practice and be inclusive. For example, use LGBT couples on service information materials.

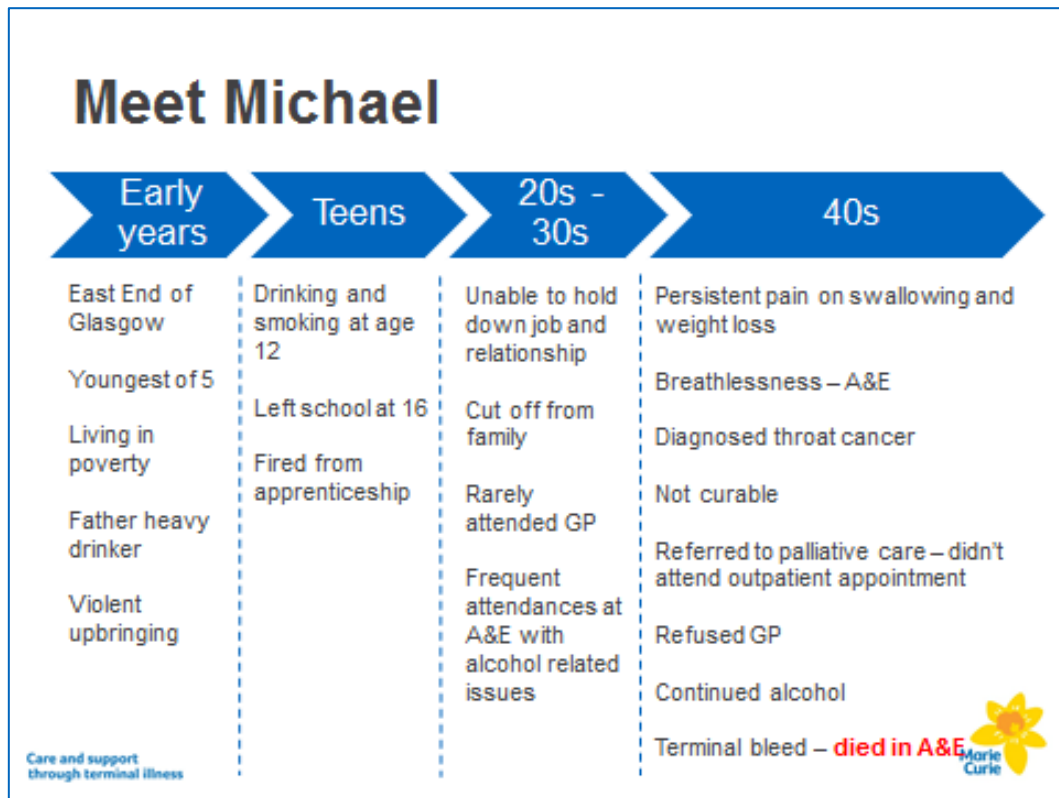
2.4. Social deprivation

Speaker – Dr Emma Carduff, Marie Curie

The LSE report found that people living in more and less deprived areas reported similar access to community-based support from nurses, social workers, hospice at home and rapid response teams. However, those in more deprived areas were less likely than those in the least deprived areas to feel they had sufficient support to care for someone dying at home; they were less satisfied with the care they receive and more frequently died in hospital, than either home or a care home.

Dr Emma Carduff, Research Lead at the Marie Curie Hospice, Glasgow, explored how people living in socially deprived areas are much less likely to access health and social care services. She also spoke about how people in Scotland's poorest communities die considerably younger than those from more affluent communities. In Glasgow, for example, people die up to 20 years younger and live in poor health for longer. They are more likely to die in hospital, more likely to need palliative care, and more likely to have numerous hospital admissions.

Dr Carduff outlined a case study, entitled 'Meet Michael' to demonstrate the potential effects of social deprivation on life chances and experiences:



Recommendations:

- More research is needed to understand access and barriers to palliative care in socially deprived areas.
- More work is needed to understand the experiences that have affected people from socially deprived communities in order to build effective service responses and resources to maximise quality of life and death.
- More public health and social support work is needed in deprived communities.

2.5. Social isolation and spiritual care

Speaker – Maureen O’Neill, Faith in Older People

Having an informal carer is the single most important factor associated with a person dying at home, whereas living alone, being unmarried or not having a carer increases the likelihood of a person dying in hospitalⁱⁱⁱ. This has serious implications on the type of care and support people receive, but also having no family or support networks can have a huge effect on people’s experience of loneliness and social isolation. Loneliness and isolation are key factors affecting both people’s physical and mental health.

A Voluntary Health Scotland briefing paper highlights that the concepts of isolation and loneliness are distinct in meaning, though often used interchangeably^{iv}:

“Isolation refers to separation from social or familial contact, community involvement, or access to services. Loneliness, by contrast, can be understood as an individual’s personal, subjective sense of lacking these things to the extent that they are wanted or needed. It is therefore possible to be isolated without being lonely, and to be lonely without being isolated.” (Age UK)

“[Loneliness is] a subjective negative feeling associated with someone’s perception that their relationships with others are deficient... [Social isolation] is a more objective measure of the absence of relationships, ties or contact with others.” (University of York research)

Maureen O'Neill from Faith in Older People spoke about how many people at the end of life, particularly frail older people, can become lonely and isolated. People can be surrounded by other people, but may still be lonely especially if their spiritual needs are not being met.

Spiritual care can often be seen as a low priority in palliative care and support, yet for many people it is a vital component of their quality of life and what 'matters to them'. Spiritual care must also not be confused with religious needs as they are also distinct and separate. A person's identity is at the heart of their spiritual needs and identity is what makes a person 'them'. This could reflect a person's life long interests, hobbies, social groups and religious beliefs.

In order to deliver spiritual care staff (and others who are supporting a person, including families) need to understand the person and this requires training and support and then the ability and time to help deliver those needs. Communication and conversation skills are key to achieving this. All those delivering care and support to a person should have the skills to support a person's spiritual needs and not just their physical ones.

We also need to make sure that staff have the time to be with people when they are ill, frail and approaching the end of life. In many care settings making the right time for people can be very difficult due to competing priorities, for example, busy hospital wards. Supporting the spiritual needs of people as they become ill and approach the end of life must be a much higher priority than it currently is. We also need to support the spiritual needs of staff working with people. Many people are often isolated or live great distances from their families. The care staff, especially in care and nursing homes, can often become close to the people they are caring for. This can have an impact on staff when that person dies. Maureen reported that there are nine deaths a week in care homes and it is important that staff are supported to deal with this.

Recommendations:

- Greater recognition of issues relating to isolation, loneliness and spiritual needs in delivering of care those living with a terminal illness and approaching the end of life.
- Training and support for staff to identify and deliver spiritual support needs for people in all care settings.
- Greater support for staff to deal with bereavement and grief issues following the death of patients in their care.



Photo 2: Delegates at the event

3. Themes from discussion

3.1. Public health

Death and loss should be clearly recognised as an important public health issue. We need to be able to have an open and honest discussion about what we want at the end of life and focus on the social, psychological and spiritual factors relating to death. These can include the experience of stigma and discrimination, grief and depression, social support, loneliness, choice over place of death, and bereavement. Health promoting palliative care approaches emphasise the need for community support and for combatting misconceptions around death, dying and bereavement.

Work around *Good Life, Good Death, Good Grief*, and *Dying Matters Week*, was highlighted.

Questions were also raised around whether this should be at both a national and a local level.

3.2. Social attitudes and stigma

There are a range of determinants and experiences that impact on a person's access to care – often a person's entire life experience can influence how they perceive, interact and ultimately engage in health and social care services. This can include mental health considerations, LGBT issues, and ethnicity.

For LGBT people, mistrust and understanding prevail in accessing health and social care services meaning that people come to anticipate discrimination and assumptions around identity and family structure. Similarly, there are issues around the complexities of religion and a person's support networks. This can all lead to increased pressure on people, their families and carers, and can cause further issues around unsupported grief and bereavement.

There is also stigma around hospices being a place where people go to die. It is common for someone to go into a hospice for a short time to receive specialist support and then return home again. Palliative care can also be delivered in a range of settings including in homes, hospitals, and care homes. Hospices also provide a range of day services and community support.

The need to challenge these myths, to make sure that people get the care and support they need was highlighted as pressing priority. Hospices have a role to play in challenging this and promoting the work they do. Delegates, including those from hospices, agreed that hospices need to go out into the community much more.

3.3. Care settings

Some people and families can often experience difficulty accessing hospices and care homes, especially those from BAME communities where many feel it is their duty to care for a person at home regardless of the complexity.

Care and nursing homes need to have much better links with local hospices and palliative care services. Many care and nursing home residents have palliative care needs or will develop palliative care needs during their time there, but are not getting the care to meet their need. Hospices should be in a position to support homes and staff to deliver palliative care. We need clear partnerships to make sure this happens.

3.4. Conditions

There are often poor links between specialist palliative care and people in other specialties. For example, people with neurological conditions can often miss out on pain management and symptom control, or those with dementia might not get care in an appropriate environment.

Delegates pointed out there is a need to make sure that everyone working in health and social care knows about their local palliative care teams and how to contact them, and understand how people who could benefit from palliative care can access it in a way that is right for them.

3.5. Communities

People at the end of life need a combination of health and social care services. These will be met by palliative care professionals, health and social care staff - across the public, voluntary and independent sectors - and communities, families and informal carers in a wide number of settings.

Delegates agreed that we all need to work together to ensure that people, families and informal carers in communities have enough information about what palliative care is, who it could benefit and how to access it.

The need to improve population health literacy so people understand more about what is available, when it is available and how they can ask for it was also considered by delegates to be very important. Delegates went on to say that there is a need to make better use of modern technology and connectivity to support people at risk of loneliness and social isolation.

3.6. Anticipatory Care Planning (ACP)

This is a process to support patients living with a terminal or long-term condition to help plan for an expected change at some time in the future, and their end of life care. Having an ACP when a person first becomes ill or at risk of becoming terminal will mean they are much more likely to access palliative care than those without an ACP.

The need to ensure that this is promoted and supported across Scotland to ensure that people's voices are heard and that their preferences, choices and wishes are realised was highlighted as a key priority by delegates.

3.7. Integration

Palliative care is now the responsibility of the new health and social care partnerships. Partnerships need to work with local communities and voluntary organisations to identify palliative care needs for all communities and terminal conditions in their localities. Representatives from partnerships at the event acknowledged that they do not know everything and requested that organisations interact with them to plan to address both the existing recognised needs and the unmet needs of people in their communities. They are keen and willing to hear from groups about their needs and how they can be met.

3.8. Human rights

While people didn't explicitly mention human rights or person-centred care on the day, this was the focus of many of the discussions. Systems and processes need to be cognisant of people's rights to access health and social care services and how those services can best work with people at the end of life. The main focus of the discussion was on how to make sure people get the care and support that they need, in a way that is meaningful to them and can allow them to live the life they want until they die.

4. Links

4.1. Marie Curie publications and resources

- Changing the conversation: Care and support for people with a terminal illness now and in the future
- LSE Report: Equity in the provision of palliative and end of life care in the UK
- Triggers of Palliative Care
 - Executive summary
 - Implications for Scotland summary
- Hiding who I am: The reality of end of life care for LGBT people
- The meaning of funeral poverty
- Palliative and end of life care for Black, Asian and Minority Ethnic Groups in Scotland – Exploring the Barriers
- Why do older people get less palliative care than younger people?

Resources for people and communities if someone close to them has a terminal illness:

- www.mariecurie.org.uk/help
- www.community.mariecurie.org.uk

4.2. Speaker Links

Voluntary Health Scotland

<http://www.vhscotland.org.uk>

Faith in Older People:

www.faithinolderpeople.org.uk

www.faithinolderpeople.org.uk/Home/spirituality.php

University of Edinburgh Primary Palliative Care Research Group

www.ed.ac.uk/usher/primary-palliative-care

St Columbas Hospice

www.stcolumbashospice.org.uk

Stonewall Scotland

www.stonewallscotland.org.uk

Greater Manchester and Eastern Cheshire Strategic Clinical Network

<http://www.gmlscscn.nhs.uk/index.php/networks/palliative-and-end-of-life-care/network-groups-palliative-and-end-of-life-care/greater-manchester-east-cheshire-palliative-end-of-life>

Through Our Eyes film resource:

www.gmlscscn.nhs.uk

www.storiestochange.org

4.3. Other useful links discussed

Strategic Framework for Action on Palliative and End of Life Care

<http://www.gov.scot/Publications/2015/12/4053>

Scottish Atlas of Palliative Care

http://www.gla.ac.uk/media/media_486122_en.pdf

Hospice UK

[The role of hospice care in Scotland](#)

Good Life, Good Death, Good Grief

<https://www.goodlifedeathgrief.org.uk>

Scottish Partnership for Palliative Care

<https://www.palliativecarescotland>

ⁱ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

ⁱⁱ <http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/population-projections-scotland/2014-based/list-of-tables>

ⁱⁱⁱ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

^{iv} <http://www.vhscotland.org.uk/wp-content/uploads/2016/05/Annual-Conference-2016-Briefing-Paper.pdf>

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through terminal illness