

Marie Curie briefing

Inequities in palliative care – Older People

11,000 people who need palliative care in Scotland each year are not accessing it. 1 in 4 people who die in Scotland miss out on the care they need. This isn't good enough and needs to change. We fully support the Scottish Government's Strategic Framework on Palliative and End of Life Care and the vision that everyone who needs palliative care has access to it by 2021.

Certain groups of people receive less palliative care than others with a comparable need. These are people who are over the age of 85, are from black, Asian and minority ethnic (BAME) backgrounds, identify as lesbian, gay, bisexual and transgender (LGBT), are from more deprived areas, are socially isolated or live alone, are homeless, have mental health needs, or are living in prisons.

Key points – Older People

- Older people are much less likely to get the palliative care they need at the end of life, when compared to younger age groups¹.
- Nearly 82% of deaths in Scotland occur in people aged over 65, and 32% in people aged over 85².
- A ten year study found frailty (27.9%) is a leading cause of death for older people with compared to organ failure (21.4%), cancer (19.3%), dementia (13.8%) and other causes (14.9%)³.
- Around 10 per cent of over 65s in Scotland are frail and a further 42 per cent are 'pre-frail'.⁴
- Nearly half of all those aged over 85 that are in hospital are in the last year of life⁵.
- Those over 75 are also likely to spend more time in hospital in the last 6 months of life when compared to younger people in the last six months of life⁶.

The World Health Organisation (WHO) has called for palliative care to be adopted in the care of older people. The WHO recognises that older people have traditionally received less palliative care than younger people and services have focused on cancer⁷. With Scotland's ageing population due to grow and those aged over 75 due to increase by 85%⁸ by 2039 this is a problem that could get worse if we do not address it now.

¹ Equity in the provision of palliative care in the UK: Review of evidence, LSE, 2014

² Vital Events Reference Tables 2014, National Records Office for Scotland, <http://www.nrscotland.gov.uk>

³ Frailty in Older People, *Lancet*. 2013: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4098658/>

⁴ ISD Scotland

⁵ Clark, D, et al, Imminence of death among hospital inpatients: Prevalent cohort study, *Palliative Medicine* 2014, Vol. 28(6) 474 –479

⁶ <http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/data-tables.asp?id=1721#1721>

⁷ Better Palliative Care for Older People, Elizabeth Davies and Irene J Higginson, WHO, 2004

⁸ Projected Population of Scotland 2014, National Records Office for Scotland, <http://www.nrscotland.gov.uk>

Evidence Base

Marie Curie commissioned the University of Edinburgh's Primary Palliative Care Research Group to carry out a study exploring access to palliative care for older people compared to younger people. The University published a report entitled *Why do older people get less palliative care than younger people?*, which can be read [here](#). An article, entitled the same, was published in European Journal of Palliative Care, which you can read [here](#).

Older people over 85 have the same care needs as younger people and should get the same access to palliative care. [However, older people have more unmet pain, less access to palliative care services than younger people with clearer illnesses](#). Older people are much less likely to get palliative care because their condition is associated with normal process of dying.

For some over 85 year olds the terminal nature of their condition was hidden from them, and there was evidence of a [lack of discussion about preferences around end of life care, including place of death](#). This was evidence of a lack of advanced care planning in these groups despite older people often have greater information needs than younger people with clearer illnesses. Some older people are not able to access information due to poor eyesight and hearing, the amount of information given, as well as information using overly medicalised language. This made it difficult for some older people to understand their situation and options open to them.

Even when death is expected referrals to palliative care are not always considered. [Physicians are less likely to refer people over the age of 85 dying from terminal conditions than those under 65](#). The reason being that physicians believe that the older a patient is the more likely that their needs are being met. When community palliative care referrals are made, delivery of them can be difficult. It also points to no clear reason for this. It suggests that this may be because services are prioritised for younger people, or because of communication issues between different care settings.

Frailty is a complex, multidimensional problem associated with decline towards dependence and death⁹. The research particularly highlighted issues surrounding frail older people and how they were less likely than all other age groups and conditions to be accessing palliative care¹⁰. [Frail older people often die without a defined single terminal illness, but they would still benefit from palliative care](#). However, they often do not have access to palliative care, palliative approaches and a 'specialist person' who can negotiate services, such as Clinical Nurse Specialists for cancer patients.

Marie Curie would like to see:

- More research into the access of palliative care by older people including how to identify older people for palliative care and how a palliative approach may be introduced for older people in a person centred way that is acceptable to patients and their families.
- More support and training for healthcare practitioners to ensure that those with frailty are identified for a palliative approach from the point of need.
- More support and training for health and social care professionals to identify loneliness, worries and emotional distress in older people and to respond with relevant responses, such as promoting resilience and social activities.
- Clearer information made available to older people to support them accessing palliative care, what services are available to them and to help with discharge planning from acute services.

⁹ *Improving the identification and management of frailty*, NHS Healthcare Improvement Scotland, 2013

¹⁰ *Why do older people get less palliative care than younger people?*, European Journal of Palliative Care, 2016

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