

Marie Curie Debate Briefing

Scottish Government Dementia Strategy

People living with dementia must be supported to live as they want to, for as long as they can. When they approach the end of life, they should be able to access the most appropriate care, advice and support.

Marie Curie urges Scottish Government to ensure that access to palliative and end of life support is a significant component of the dementia strategy.

Key facts about dementia and terminal illness

Research undertaken by Marie Curie found that by 2040¹:

1. **People dying from dementia** as the main underlying cause of death is **expected to rise by 185%**
2. The number of **people dying from multi-morbidities each year (e.g. dementia and at least one other terminal condition)** will have risen by **82%**, resulting in highly complex health and social care needs, including palliative care
3. **10,000 more people** will be dying with palliative care needs each year by 2040, **a large proportion of these are expected to be from dementia**
4. **Two thirds will be dying in community settings by 2040**; in people's own homes, care homes and hospices

We also know that:

- Dementia has been among the leading causes of death in Scotland for several years²
- Significantly more women die with dementia as a leading cause of death than men³
- Between 70-90% of people living in Scotland's care homes have dementia⁴

Marie Curie is calling for the Scottish Government's Dementia Strategy to:

1. Include **accessible, tailored palliative and end of life support for people affected by dementia, including bereavement support**, accompanied by a clear, measurable implementation plan
2. **Align with, and inform, the Scottish Government's upcoming palliative and end of life care strategy**
3. Be **sustainably funded** to enable equal access to free health and social care for people with dementia⁵, in people's own homes and in care homes
4. **Invest in and upskill health and social care teams supporting people affected by dementia through palliative and end of life care training, especially in care homes, and support anticipatory care planning**

¹ How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. Authors: Anne M. Finucane, Anna E. Bone, Simon Etkind, David Carr, Richard Meade, Rosalia MunozArroyo, Sébastien Moine, Aghimien Iyayi-Igbinovia, Catherine J Evans, Irene J Higginson and Scott A Murray doi: 10.1136/bmjopen-2020-041317

² National Records of Scotland: Vital Events Reference Tables 2017-21

³ National Records of Scotland: Vital Events Reference Tables 2017-21

⁴ Alzheimer Scotland: 'Delivering Fair Dementia Care for People with Advanced Dementia' report, 2019

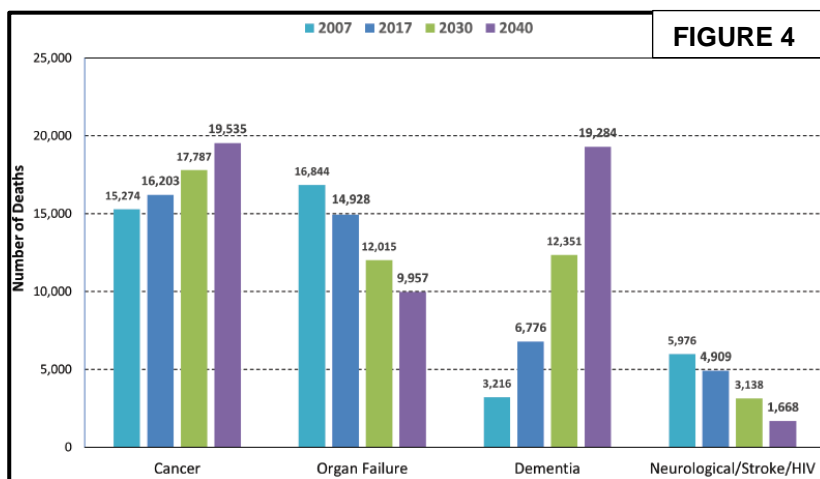
⁵ Alzheimer Scotland: 'Delivering Fair Dementia Care for People with Advanced Dementia' report, 2019

Challenges for dementia and palliative and end of life support

Not enough people with dementia in Scotland are accessing palliative care and end of life care when they might benefit from it. [Research from the University of Edinburgh found that 4 out of 5 people with frailty/dementia do not get the palliative support they need.](#)

Barriers being faced by those with dementia in accessing care at different stages of their illness and at including end of life include:

1. **Recognition** – dementia is often not thought of as a terminal illness. This means that anticipatory care planning may not begin early enough, the impact of dementia and the impact of dementia on the way that someone experiences other health issues is not taken into account.
2. **Inequality of access** – people with dementia face discrimination in care due to inconsistencies in access to social care support and lack of recognition of their care needs as health care needs. Hospices and specialist palliative care services are often underused by people living with dementia despite specialist staff and volunteers having the training and skills needed to deliver services to people with dementia.
3. **Inconsistent quality of care** – people with dementia are more likely to be admitted to hospital compared with older people who do not have dementia. There are inconsistent standards of dementia care across Scotland. There can also be inappropriate interventions, poor pain management, a lack of continuity of care and a lack of support for carers.



The number of people dying with dementia is going to significantly increase. By 2040, it's expected that those dying with dementia as the main underlying cause of death is going to three times higher than currently. Figure 4 from Marie Curie research evidences a 185% increase in dementia deaths, as well as increase in cancer deaths.

Multi Morbidities

Marie Curie research shows that multi-morbidities are becoming the norm in Scotland, starting earlier in life and rising steeply with age.

Multi-morbidity is defined as two or more registered causes of death from different disease groups (such as dementia, cancer, organ failure).

By 2040, the number of people who will die with multi-morbidities will increase by 82% to over 28,600, accounting for 43.5% of all deaths or nearly half (46%) of palliative care deaths.

People living with dementia must be supported to live their lives as they want for as long as they can. When they approach the end of life, they should be able to access the most appropriate care, advice and support.

Marie Curie urges the Scottish Government to ensure that access to palliative and end of life support is a significant component of the dementia strategy

What needs to happen?

1. Financial support for people affected by dementia

Unequal, crippling health and social care costs

Marie Curie supports Alzheimer Scotland's Fair Dementia Care campaign, which highlights the substantial health and social care costs for people affected by dementia.

People dying with dementia should not have to pay for their health treatment; they should have access to the palliative care they need on an equal basis to people dying with other diagnoses of terminal illness.

Scottish Government must remove the current system of social care eligibility criteria and move Scotland's social care system away from a focus on risk, to enabling people dying from dementia to access the care and support that they need to lead a full life

This principle should also apply when a person is assessed or reassessed for care as they move toward the end of life, and a focus on quality of life and supporting people to live as well as possible and meeting their wishes where possible

Carers

The role of being a carer for someone who is living with dementia has a huge impact on the life of the person they are caring for, as well as the financial, physical and emotional wellbeing of the carer themselves.

A person can live for years with dementia, placing significant long-term physical, emotional and financial burdens on carers.

Costs for unpaid care are usually categorised into three main areas⁶, and **have risen sharply during the pandemic, exacerbating the cost of living crisis for carers of people living with dementia, and multi-morbidities:**

1. **Work related** (e.g. changes in employment such as going part-time or giving up work entirely)
2. **Carer time costs** (related to time investment required by carers)
3. **'Out of pocket costs'** (direct outgoings including transport, food, medicines)

Once a caring role comes to an end, it can have a significant impact on the carer's wellbeing, financial position, relationships and virtually every aspect of their life.

2. Health and social care service implications

Training is a vital element of professional development, knowledge and experience building but **many health and social care professionals face significant challenges accessing and undertaking palliative and end of life care training**. This can result in (early) referral opportunities being missed due to lack of knowledge, and patients dying from dementia missing out on the care they need.

A Palliative and End of Life Care Education and Training Framework by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) to support health and social care professionals has been developed, but it is unknown how workforces are performing against the framework's principles and what structure is in place (if any) to ensure consistent training delivery.

Care home staff, and the wider social care workforce have little, if any, training in palliative and end of life care. Yet they are expected to deliver it on a daily basis in people's homes and in care homes to patient's with often very complex needs.

As part of the Dementia Strategy, health and social care workforces should be reviewed against the NES/SSSC and Palliative and End of Life Care Framework to understand current care delivery and areas for improvement

The Dementia Strategy must support mandatory palliative and end life care training for all health and social care staff working with people dying from dementia to ensure high, consistent standards of care.

⁶ Gardiner, C et al *Equity and the financial costs of informal care giving in palliative care: a critical debate* BMC Palliative Care 2020

Resource is one of the main obstacles for being unable to release staff for palliative and end of life education and training, which has been exacerbated throughout the pandemic by additional demands on acute settings, primary care and social care.

There must be a flexible, ongoing palliative and end of life care education programme established which reflects a blend of face-to-face and digital learning to provide better training for everyone delivering palliative care to people dying from dementia, including families and carers

3. Bereavement support

The death of someone from dementia, whether sudden or expected, can have a long-lasting impact on families and carers. But due to cognitive decline in patient's dying from dementia, there must be recognition that families and carers may start grieving for the person even before they have died.

The dementia strategy must include a commitment to accessible, tailored bereavement support, which reflects individual needs

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2. **Align with, and inform, the Scottish Government's upcoming palliative and end of life care strategy**
3. Be **sustainably funded** to enable equal access to free health and social care for people with dementia⁷, in people's own homes and in care homes
4. **Invest in and upskill health and social care teams supporting people affected by dementia** through palliative and end of life care training, especially in care homes, and support anticipatory care planning

Further information:

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⁷ Alzheimer's Scotland: 'Delivering Fair Dementia Care for People with Advanced Dementia' report, 2019