

# Proposal on a Right to Palliative Care (Scotland) Bill

Summary of our response  
June 2024



## Background to the consultation

In March 2024, Miles Brigg MSP launched a public consultation on a proposal for a Members Bill to provide anyone in Scotland with a terminal illness, a legal right to palliative care. The term palliative care is used to describe the care provided to someone following a diagnosis of a terminal illness. This includes helping to manage and relieve symptoms and overall allowing them to maintain a good quality of life. Palliative care does not just mean end-of-life care and can last from weeks to several years. Palliative care is often misunderstood and poorly defined, and as such this was a key area looked at within the consultation.

The aim of the bill is to ensure that everyone who is eligible for palliative care who wishes to receive it can do so, regardless of where they are in Scotland or which terminal illness they have. It is hoped that a Bill making this a legal right will create a stronger foundation for people to be aware of and access the care and support they require. A similar legal right exists in England, introduced in 2022 as part of an amendment to the Health and Care Act (2022). The proposal is for a similar right to be introduced in Scotland.

Key intentions put forward in the proposal for this Bill include:

- **Eligibility** - people of all ages living in Scotland with a terminal illness would be able to access palliative care
- **Timing** – the proposal is for the right to apply from the moment of a terminal illness diagnosis
- **Location**– a right to palliative care is proposed to be open to anyone in any care setting including at home
- **Responsibility** – delivery of palliative care should be through health and Social Care Partnerships.

These areas formed the basis of the consultation, with five key questions for responses to answer. Age Scotland and About Dementia submitted a joint response to the consultation, which can be read in full [here](#). This summary will focus on the views and thoughts expressed by About Dementia members.

## Our Engagement

At Age Scotland and About Dementia, we believe that amplifying the voices of older people, people living with dementia and unpaid carers is vital to building impactful policy responses. As such, our response to this consultation involved various methods of engagement to ensure the voices of those with lived experience informed and created the foundations of our discussion. These included:

- **Online survey** – we sent a short digital survey to Age Scotland supporters, receiving 468 responses
- **Policy drop-in and engagement** – We hosted a Policy Drop in on Palliative Care and invited Marie Curie to speak to About Dementia Members. For those members who could not attend, they were invited to share their views via email



Members of the About Dementia team also attended two roundtable discussions organised by Marie Curie Scotland to discuss the proposed Right to Palliative Care. One focused on older people (chaired by Colin Symth, MSP), and the other on unpaid carers (chaired by Pam Duncan-Glancy, MSP).

### Key Findings and recommendations

Overall, our members strongly support a legal right to palliative care to be introduced in Scotland. On the whole, older people, people living with dementia and unpaid carers felt this was an important aspect of care which can offer a vital lifeline of support for people with a terminal illness and their support networks. Many voiced their surprise that access to palliative care is not already a legal right in Scotland.

We know that the topic of palliative and end-of-life care is a sensitive and potentially challenging issue for people living with dementia and their families and carers to discuss. From our discussions and engagement there was a consensus that a legal right to palliative care would positively impact people living with dementia and their carers. Increased support from the moment of a diagnosis, including with symptom management throughout their dementia journey would enable people with dementia to live well and maintain full lives, a goal we share with our members.

Whilst our response overall supported the content of the draft proposal for the Bill, several key findings from our discussions with our members helped inform some recommendations which we believe would strengthen the proposed Bill.

#### *Education and awareness of palliative care*

About Dementia members spoke of the common belief that dementia is not a terminal illness, and as such does not qualify for palliative care. For example, one member spoke of being unsure how to answer when completing a form which asked if they have a terminal illness. This lack of understanding that dementia is classed as a terminal illness, and that those living with dementia would be eligible for palliative care, creates a barrier for people accessing potential support. It was felt that creating a legal right to palliative care could benefit people living with dementia and unpaid carers. To be successful there must be a push for greater

education and awareness of dementia as a terminal illness, and what palliative care is available for those living with a diagnosis.

We therefore recommend that:

- The Scottish Government’s strategy delivery group for the new dementia strategy,<sup>1</sup> should look at increasing education and awareness of dementia as a terminal illness and what palliative care options are available, including support with managing symptoms. For example, this could include a public awareness campaign, co-produced with those with lived experience, within the next strategy delivery plan from 2026.
- Mandatory training is provided to all health care professionals into how to have more open conversations about palliative care and future care plans for anyone living with a terminal illness, including dementia.

### *Making implementation as simple as possible*

A key concern raised in our consultation response, is that a legal right is meaningless unless it is implemented and is effective in practice, not just on paper. To illustrate this, we use the example of the Scottish Government’s commitment to everyone with a dementia diagnosis receiving a minimum of **12 months post-diagnostic support**. Despite this commitment on paper, the proportion of those receiving a diagnosis and a full year of PDS has never reached 50% in the decade since the policy was introduced.<sup>2</sup> We don’t want to see a right to receiving palliative care repeating this pattern. To avoid this, we recommend that the legal right **builds upon existing frameworks**, such as the post-diagnostic support system. For example, by reviewing what is included within dementia post-diagnostic support, ensuring there is greater considerations around palliative care, including earlier discussions of future care planning and end of life care, this could help to bridge the gap that many people with dementia feel following the end of PDS. We believe that by improving access to PDS to address the existing issues, a PDS model could help create a smoother transition from palliative to end of life care for people living with dementia.

### *Definition of palliative care*

As discussed at the start of this briefing, the definition of what palliative care is, is not always clear. One of the key questions asked in the consultation was for views on the World Health Organisation’s definition of palliative care (see below), and if this was a suitable definition to be the basis of the legal right in Scotland.

A key finding from the engagement is that there was a common misunderstanding of what palliative care is, including the difference from end-of-life care. As Marie Curie explains, “*end of life care is part of palliative care [...] people often have*

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<sup>1</sup> Scottish Government (2023). Dementia in Scotland: Everyone’s Story. [Link](#)

<sup>2</sup> Public Health Scotland (2024). Dementia post-diagnostic support. Local Delivery Plan Standard; Figures to 2021/22. [Link](#)

*palliative care for some time before getting end of life care.”*<sup>3</sup> We therefore believe that a **clear, accessible** and **empowering** definition is required to clarify what palliative care is, so that those who have the right are aware of what they have a right to and when. Based on our engagement, we support the use of the World Health Organisation’s (WHO) definition of palliative care. There was strong support amongst members for the holistic nature of the definition, with the inclusion of not just physical symptoms, and the specific acknowledgement on those receiving a diagnosis as well as their families and supporters.

However, we feel that the WHO definition should be amended as follows, based on discussions with About Dementia Members, to make sure it is clear and accessible. Suggested amendments are shown in bold below.

*“Palliative care is an approach that improves the quality of life of **people** of all ages, families, **and unpaid carers** who are facing problems associated with life-threatening illness. It prevents and relieves **pain and symptoms** through early identification, correct assessment and treatment of pain and other problems whether physical, psychosocial or spiritual. **It provides the opportunity to access care at any point from the moment a diagnosis of a life-threatening illness is received and includes but is by no means exclusively end-of-life care, which refers to care in the final year or less of someone’s life.**”*

### *Responsibility and delivery of palliative care*

In response to the consultation question on how a right to palliative care should be implemented, we believe that Health and Social Care Partnerships (HSCPs) should continue to be responsible. This was supported by About Dementia members during our engagement. Other recommendations made regarding the delivery of a right to palliative care include:

- HSCPs must **publish data** on the number of people accessing palliative care each year. We recommend that this is **broken down by diagnosis** so that there is evidence of the number of people living with dementia and other conditions who receive palliative care in Scotland each year.
- We support Marie Curie Scotland’s call for **‘minimum service standards’** for palliative care. Having minimum standards for services would allow everyone receiving palliative care to access the same level of services and support as anyone else, regardless of where they live. These standards should be clearly written and easily available to everyone.
- There is a lack of specialist nursing staff to deliver palliative care for people living with dementia in Scotland. We recommend that the **‘admiral nurses’** model,<sup>4</sup> currently used across England and Wales, or something similar is considered to address current gaps in Scotland. The first admiral nurse in

<sup>3</sup> Marie Curie Website. What is end of life care? [Link](#)

<sup>4</sup> Dementia UK. What is an Admiral Nurse and how can they help? [Link](#)

Scotland is currently being piloted in Orkney. If this is successful, we recommend that this is introduced across more areas. This would help to ensure that along with a legal right to palliative care, people across Scotland living with dementia genuinely feel that they have better access to support.

### *Other key recommendations*

From our discussions to inform this response, and our previous engagement work, we offered some additional recommendations for the proposed right to palliative care Bill to ensure that it is supportive for people living with dementia and their carers.

- We support the proposal's commitment to involving people with lived experience throughout the development and implementation of the policy. We recommend following a **human-rights based approach** to this process, using the PANEL principles of participation, accountability, non-discrimination and equality, empowerment and legality.<sup>5</sup>
- If areas of delivery depend on the third sector (voluntary organisations and charities) this must be properly funded over the long term.
- Everyone entitled to palliative care should know that they are entitled to it. Services and organisations should increase awareness of what palliative care is and who can access it, including people living with dementia.

### **Next Steps**

This is the first stage (out of five) for a Members Bill to the Scottish Parliament. All responses will be analysed, and a new proposal written based on that. MSPs will then have the chance to vote on if they think it is a good idea or not. If 18 MSPs sign up it will then go to parliament for wider discussion. About Dementia will keep members posted on the progress of the bill at the next stages

In the area of palliative care, the Scottish Government is currently in the process of developing a new palliative and end of life care (PEOLC) strategy, overseen by a strategy steering group.<sup>6</sup>

### **Further information**

If you would like any more information on our response to this consultation or any of our policy work, please contact us at [aboutdementia@agescotland.org.uk](mailto:aboutdementia@agescotland.org.uk)

To keep up to date with everything about dementia is up to, you can follow us on X: [@aboutDementiaSc](https://twitter.com/aboutDementiaSc)

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<sup>5</sup> Scottish Human Rights Commission. A human rights-based approach: an introduction. [Link](#)

<sup>6</sup> Scottish Government (2023). *Palliative and end of life care strategy aims, principles and priorities*. [Link](#)