

Summary of our response to the Scottish Government's draft of a new Palliative Care Strategy

January 2025

Background

We have provided feedback on the Scottish Government's draft of a new palliative care strategy, titled 'Palliative Care Matters for All'. Scotland's population is getting older, and as a result, the demand for health and social care, including palliative care, is increasing.

Definitions

Palliative Care – Care (physical, mental, spiritual, social) aiming to improve the quality of life for those living with a life-threatening or terminal illness and their families and carers. Palliative care can begin as soon as a diagnosis is received and continue through to end-of-life and beyond through bereavement support.

End-of-life Care – part of palliative care for people as they near the end of life, usually in the last year. It aims to help people die with dignity and support those around them.

This consultation asked for our thoughts on the aims, cornerstones, outcomes and actions of the strategy and if we think the strategy content will help to improve experiences of palliative care in Scotland.

This summary will cover some of the key concerns and asks we put to the Scottish Government to consider when creating the final strategy. This will include our focus on the impact on people living with dementia and older people from ethnic minority and other marginalised communities. Our full response is available [here](#).

To inform our response, we used insights from previous engagement sessions discussing the proposed Right to Palliative Care (Scotland) Bill and the Assisted Dying for Terminally Ill Adults (Scotland) Bill carried out in 2024. This included insights from discussions with About Dementia members and surveys from wider Age Scotland supporters. We also carried out one piece of new engagement specifically about this strategy with the **Scottish Ethnic Minority Older People's Forum [SEMOPF]**.

Strategy Aims:

1. Adults and children in Scotland have more equitable access to well-coordinated, timely and high-quality palliative care, care around dying and bereavement support based on what matters to them, including support for families and carers.
2. Scotland is a place where people, families and communities can support each other, take action and talk more openly about planning ahead, serious illnesses or health conditions, dying and bereavement.
3. Adults and children have opportunities to plan for future changes in their life, health and care with their families and carers.

We generally support the three aims of the strategy; however, we raised several concerns in our response:

1. There needs to be a **clearer definition** in the strategy of what 'equitable access' to palliative care looks like
 - People need to know what they should expect from palliative care services
 - Minimum Service Standards for palliative care need to be created to enable equitable access. This means everyone should know the minimum standard of service they should expect to receive
2. We have concerns that the aims cannot feasibly be achieved in the five-year time frame, especially without dedicated resources
3. The evidence used to inform the development of the strategy didn't include those living with certain incurable conditions such as dementia who may be accessing palliative care services
4. We are disappointed that the strategy did not explain who would be responsible for delivering each part of the strategy and how they would be held accountable

Strategy Outcomes

The draft strategy includes **eight outcomes** which are designed to deliver the aims of the strategy. Each outcome includes the actions which will be taken to achieve it. These are lengthy and complex. Therefore, below we are highlighting some of the main points we raised in our consultation response about some of these outcomes. For full details, please see our full response available [here](#).

We generally agree that the outcomes are along the right lines of what is needed to improve palliative care in Scotland. However, the main issue we raised is that we feel that the outcomes and actions are more like a series of principles to follow, rather than measurable outcomes that will bring real change. The outcomes are currently quite

ambiguous about what these improvements will look like in practical terms. For example, one outcome is that the *'quality and experiences of care around dying and bereavement support are improved [...]*', however, it isn't clear what improved quality and experiences would look like. We asked that the outcomes be improved to follow the **SMART principles**. This means they need to be **S**pecific, **M**easurable, **A**chievable, **R**elevant and **T**ime-bound. Following these principles will make the outcomes, and therefore the strategy more likely to improve people's experiences of palliative care in Scotland.

Dementia

One of the areas we focused on in our response was the impact on people living with dementia and their support networks. From previous discussions we've had with our members, we know that people living with dementia are often unsure if palliative care is available to them. This is similar more widely with one poll finding that **58%** of the public, did not believe that dementia is a terminal illness,¹ and therefore eligible for palliative care. Therefore, whilst we support the strategy of improving understanding, information, and awareness around palliative care, this needs to focus on those living with conditions who might not be aware they are eligible. This is especially important given the projected increase in the number of people who will be living with dementia in the future. If the strategy's aim to ensure there is equitable access to palliative care in Scotland is to be achieved, then increasing understanding of who is eligible and when is critical.

Some of the other points we raised included:

- The data collected when monitoring the implementation of this strategy should **be broken down based on the condition** that someone receiving palliative care is living with
 - Data should also be collected about **when** palliative care is started (e.g., immediately after diagnosis or in the more advanced stages of the condition)
- Early identification of dementia and associated palliative care needs is essential. We noted that in the early stages, it can be easier to mask symptoms of dementia, therefore there needs to be better training for health and social care professionals.
 - Tools for identifying palliative care needs should include earlier signs of dementia, not just advanced symptoms

Marginalised Communities

As part of our response, we looked at the potential impact of the strategy on older people from marginalised communities, including individuals from the LGBTQ+ community and those from ethnic minority backgrounds. The strategy does mention the importance of ensuring that palliative care is accessible to these groups and that barriers to access are addressed. However, like most strategies, we feel that it doesn't properly explain what these barriers are and how they will be overcome.

¹ EMBED-Care Public Opinion Poll (2022). [Link](#)

The older people we engaged with from the Scottish Ethnic Minority Older People's Forum (SEMOPF) and the LGBTQ+ Scottish Older People's Network identified the following barriers to accessing palliative and end-of-life care, which we highlighted within our response.

- For members of the **LGBTQ+ community**, there is often still a **mistrust** around accessing healthcare services due to **historical discrimination** many faced e.g., during the HIV/Aids crisis. This can make people more reluctant to access the care and support they are eligible for.
 - Support networks might look different to the traditional concept of a 'family' for LGBTQ+ individuals. If staff do not understand and respect this, this can put people off from accessing care
- **Lack of understanding** of what palliative care is, how it is different from end-of-life care and how to know if you are eligible
 - This can especially be a problem if there is **no direct translation of 'palliative care'** into someone's native language
- Healthcare staff **not understanding or respecting cultural and religious practices**.
 - Examples include certain cultures requiring only female carers; some communities having more family to visit to recite prayers which might cause disturbance to other patients; those who follow the Muslim faith not wanting the legs to face Mecca whilst sleeping

Some of the solutions put forward to address these barriers include:

- To address barriers for LGBTQ+ individuals, there should be some kind of **marketing campaign** clearly stating that palliative care services support and include LGBTQ+ individuals
 - This should be backed up by staff from the LGBTQ+ community supporting the services where possible, or staff with training accreditations who are **genuine allies**
- Information about palliative care must be accessible to everyone e.g., in different languages and with clearly understandable explanations
- There needs to be **clear communication** about palliative care in a way that suits the individual. This must include things such as hospital/hospice visiting times
 - Language should be kept as **simple** as possible with **no jargon**
- **Better training** on religious and cultural preferences for those delivering palliative care
 - Messaging option (like the sign saying 'not all disabilities are visible') to show when someone has religious/cultural requirements for their care

- Not taking a ‘one size fits all approach’ to improving understanding and being culturally respectful

We have put these to the Scottish Government through our response. We hope that they will take these points on board to ensure that this strategy makes a tangible difference to everyone’s experience of palliative care, especially for those who may face additional barriers.

What happens next?

This consultation has looked at the draft palliative care strategy. Once all submissions are received, the Scottish Government will analyse the responses, producing an analysis report. According to the consultation paper, the Scottish Government will then consider all the responses and will use them to inform the final strategy and the delivery plans for the strategy.

If you would like any more information on our response to this consultation or any of our policy work, please contact us at policy@agescotland.org.uk

Further information

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