

## Palliative Care Matters for All: Strategy Consultation

Palliative Care Team, Scottish Government

10<sup>th</sup> January 2025

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Age Scotland is the national charity for older people in Scotland, providing support to, and representing the needs and views of over 50's across a range of areas. We work to improve the lives of people over 50, amplifying their voices and promoting their rights and interests. About Dementia is Age Scotland's Dementia Policy and Practice Forum. We work to ensure that the voices of people living with dementia and unpaid carers are heard at a policy level by building our policy responses with the voice of lived experience at the core. We believe that the people who face the challenges are also best placed to discuss the solutions.

### About this consultation response

This five-year strategy (2025-2030) builds on the Scottish Government's previous palliative care strategies from 2008 and 2015. Through the aims, outcomes and actions stated in this strategy, it is expected that adults and children, as well as their families and carers, will have better experiences of palliative care; care when someone is dying; and bereavement support. We welcome the opportunity to respond to the draft of this new palliative care strategy. This is a joint submission on behalf of Age Scotland and About Dementia.

To inform our response, we used insights gathered from older people during previous discussions around the topics of palliative care and assisted dying. This has included speaking to people living with dementia and their unpaid carers; ethnic minority community members and individuals identifying as LGBTQ+.

We hope that the valuable insights we have offered within this response are used to inform the final strategy. This must sufficiently reflect the needs of older people, especially people living with dementia, their unpaid carers, and those from marginalised communities.

## Section A: Overall strategy

**1. Do you agree with the aims for this strategy? Please add any comments you have about the strategy aims here.**

### Agree

Overall, we support the three aims of the strategy. We strongly agree for the need for more equitable access to palliative care. This must not just be based on location, but also equitable access regardless of diagnosis or the community someone belongs to. For older people living with certain incurable conditions such as dementia, and for those from communities where culturally the concept of palliative care might not be as familiar, there are greater challenges to accessing palliative care services. This must change so everyone can access their human right to the “*highest attainable standard of physical and mental health*”.<sup>1</sup> One concern we have with this first aim is the lack of a definition of what ‘equity’ means within this strategy. ‘Equitable access’ is futile if people don’t know what care they should expect to receive. We reiterate our previous ask for the creation of ‘minimum service standards’ for palliative care.<sup>2</sup> These will ensure that everyone is aware of the minimum standard of care they should expect, therefore defining what equitable access looks like.

We strongly agree with the aim for Scotland to be a place where everyone talks more openly about planning ahead, serious illness, dying and bereavement. We often hear from older people, especially those affected by dementia, that these are challenging conversations to have. Without addressing this, access to palliative care for those who need it will not improve.

***“It’s very difficult speaking to people about it, they don’t want to know about it and that’s fine. But there needs to be a way that we can start to involve them and encourage them.”***

**– Unpaid Carer,  
Speaking at About Dementia Policy Drop-in,  
May 2024**

We strongly agree that working in partnership across health and social care, local authorities and wider communities is essential for the strategy aims to be achieved. We recommend that this should include third-sector and community organisations beyond those immediately advertised as ‘palliative care’ organisations. For example, peer support groups and meeting centres for people living with dementia and unpaid carers are

<sup>1</sup> World Health Organisation Website (2023). Human Rights. [Link](#)

<sup>2</sup> Age Scotland (2024). Right to Palliative Care (Scotland) Bill – Consultation response. [Link](#)

important places to work in partnership with, as they provide opportunities for signposting and providing information about palliative care services.

Whilst we agree with the overall aims of the strategy, we have some concerns about the feasibility of achieving the strategy aims and outcomes within the five-year timeline. As it currently stands, we echo Marie Curie's<sup>3</sup> concerns about the practicality of the strategy, especially around the aims and outcomes being vague and difficult to measure. Unless these concerns are addressed, it feels unachievable for this strategy to be realised within just five years. Furthermore, with Scottish Parliament elections due to be held in May 2026, this could mean that a new government comes into power for the remaining four years of the strategy who might have different priorities.

## Strategy Development

We support the range of evidence used to inform the development of the strategy; however, we feel that there are significant gaps. For example, in the 'Healthcare Improvement Scotland: Gathering View Report on Palliative Care', more older people should've been asked about their views of palliative care. We acknowledge that older people may have participated in some of the other groups if this also applied to them, however, we feel that just two older people within this group is not going to get a sufficient picture of the views of palliative care from older people in Scotland. Additionally, it appears that the views of people living with certain conditions who might have specific palliative care needs, such as those living with dementia, were not gathered. Therefore, we feel that there are key gaps in the data being used to inform this strategy. We hope that the insights offered in this response, which are informed by the voices of older people including those living with dementia and those from seldom heard groups, will contribute towards addressing these gaps and we ask that these are used to inform the final strategy.

## Strategy Delivery

We agree with the general plan for delivering the strategy. We hope that the delivery plan to be published alongside the final strategy will provide clear and actionable steps to realising the strategy's aims in practice. We are disappointed that this draft strategy does not provide clarity around responsibilities and accountability for delivering each action. Explicit clarification of these is critical to ensure that this strategy does not result in a lack of change in practice, despite good intentions on paper.

Finally, we support the plan to publish an annual palliative care report on the Scottish Government website outlining the progress on delivering the strategy. This must be publicly advertised and provided in accessible formats such as easy read. We also ask that

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<sup>3</sup> Marie Curie (2025). *Response to Palliative Care Matters for All*

the data collected for these reports, including measures of access to palliative care and care quality indicators, be disaggregated by diagnosis to help address existing data gaps.

## 2. Do you agree with the strategy cornerstones which form the basis for the strategy and delivery plans? Please add any comments you have about the four strategy cornerstones here.

### Agree

Whilst we generally agree with the strategy cornerstones, we feel that the different layers of strategy (aims, cornerstones, outcomes, actions) could be confusing for those without in-depth knowledge. We suggest that a flowchart could be developed and included at the start of the strategy to demonstrate how each of these levels interact with each other.

#### Cornerstone 1

Whilst we broadly agree with cornerstone 1, we suggest that where ‘shared decision-making’ is mentioned, **supported decision-making** (SDM) is also stated, alongside an explanation of what this is. Supported decision-making is an approach to decision-making which provides sufficient support to people so that they can make their own decisions and exercise their legal capacity. SDM involves putting the person’s will and preference at the centre of all decisions.<sup>4</sup> This is especially important for disabled people including those living with dementia where it is often assumed that they cannot make their own decisions, for example, about palliative care. We believe that supported decision-making, alongside shared decision making where appropriate, should be central to palliative care.

We agree with cornerstone 1 in stating that involving people close to the person receiving palliative care is important. From the older people we have spoken to who are part of the LGBTQ+ community, this is an area they often feel negatively impacts them. For many LGBTQ+ people, those close to them might look different to the traditional family and are instead often referred to as their ‘chosen family’. It is vital that when accessing palliative care, everyone who wants to can have those who are important to them involved in their care, regardless of what this might look like.

#### Cornerstone 2

We agree with cornerstone two that a population-based approach to palliative care is essential. However, fundamental data gaps need to be addressed for a reliable picture of palliative care needs to be established. For instance, there are currently significant data gaps in the number of people living with dementia and the stage at which a diagnosis is received. Without addressing these gaps to gain a true understanding of the number of people in Scotland who could be eligible for palliative care support, cornerstone 2 cannot be fully achieved.

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<sup>4</sup> Scottish Commission for People with Learning Disabilities (2024). *Supported decision-making in Scotland: discussion paper*. [Link](#)

## Cornerstone 3

We strongly agree with cornerstone 3. Many older people, especially those living with long-term conditions such as dementia, experience breaches of their human rights when it comes to accessing support for their physical or mental health. Often, people are not even aware of this. We agree that through the delivery and implementation of this strategy, inequalities in access to palliative care must be addressed and diversity respected.

We strongly support the proposal for there to be a **legal right to palliative care** in Scotland, as put forward by Miles Briggs MSP in 2024. A legal right to palliative care, alongside minimum service standards, would help to ensure this strategy is implemented in practice. Read our full response to the consultation [here](#).

## Cornerstone 4

We agree that strong cross-sector leadership will be critical for this strategy to be implemented successfully in practice. Clear roles, responsibilities and accountability are essential, but this is often easier said than done. Fundamental change in the way health, and social care is delivered is needed for the aims of this palliative care strategy to be realised. This might look like the proposed National Care Service (NCS) as suggested in cornerstone 4. However, change must not wholly rely on the introduction of the NCS. Reform must happen now as the delivery of care is only getting worse as we hear daily through our helpline for older people.

## **Section B: Strategy outcomes**

**3. Do you agree with strategy outcome 1 and the proposed actions being developed to deliver this outcome? Please add any comments you have about outcome 1 and its actions here.**

### **Agree**

From our work with older people, we know that there is often a misunderstanding as to what palliative care involves, who can access it and when. Many incorrectly believe that palliative care is only available at the final stages of someone's life.

***“Well, I mean, I've always thought of palliative care as being literally, you know, the days before somebody dies”***

**– Person living with dementia**

We agree that awareness and understanding of palliative care must be improved. This information should be provided at the time someone receives a diagnosis of an illness that is likely to end their life. However, we caveat this with the need for there to be sensitivity around not overwhelming individuals and their support networks during an already challenging time. Information should be offered but healthcare professionals

should make it clear that it doesn't have to be considered at that moment and can be referred to later.

We agree that information about palliative care must be provided in many formats. This must include easy-read, large-print, braille and in other languages. Whilst information via social media might not be as accessible for older people, it could be a positive space to reach younger people who can gain better knowledge for when they age and could also pass information on to older people in their lives. Information should be available in the suggested community settings; however, this should also include dementia meeting centres and peer support groups, older people groups and libraries. Finally, in relation to health and social care staff providing information, this must include dementia post-diagnostic link workers.

## Dementia

One of the biggest areas we feel this strategy needs to target is improving understanding of who is eligible for palliative care. Palliative care aims to improve the quality of life for people living with a life-threatening or serious health condition. Therefore, this implies that people living with a diagnosis of dementia and their carers should be eligible for palliative care. However, this is currently not the case. One poll found that **58%** of the public did not believe that dementia is a terminal illness.<sup>5</sup> Even those living with dementia are often not sure if they are eligible for support for those with a terminal illness:

***“I think people haven't realised that people die from dementia. People don't talk of dementia as a terminal illness [...] I was filling out a form the other day [...] and it says, do you have a terminal illness? And I couldn't work out what the answer was. I didn't know whether it was appropriate to put Yes, I have Alzheimer's or not. I still am not sure really.”***

**- Person living with dementia**

Something we have heard time and again, is that dementia is not given the same parity as other incurable conditions in terms of care, support and government funding. Despite the potential that palliative care could offer to people living with dementia, this group are often disadvantaged in accessing timely palliative care.<sup>6</sup> The significant projected increase in deaths from dementia in Scotland by **77%** from 12,658 in 2021 to over 22,000 in 2040,<sup>7</sup> is strong evidence that people living with dementia should have equitable access to palliative care. There are ongoing debates about when the best time is for people living with dementia to start receiving palliative care. Whilst some may see it only as applicable in the advanced stages of the condition, we argue that for the aims of improving someone's quality of life to be achieved, palliative care should be available

<sup>5</sup> EMBED-Care Public Opinion Poll (2022). [Link](#)

<sup>6</sup> Gilissen et al (2021). *Earlier Initiation of palliative care in disease trajectory of people living with dementia: a scoping review protocol*. [Link](#)

<sup>7</sup> Scottish Government (2024). *Palliative care strategy – population data and research*. [Link](#)

from the moment a dementia diagnosis is received through to the end of life care when the condition is at its more advanced stage.<sup>8,9,10</sup> When palliative care is started should be down to an individual's preference.

## Challenging conversations

The quote below from our survey looking at issues around palliative care demonstrates that conversations around terminal illness, death and bereavement are challenging but need to be had.

***“Death is such a taboo subject [...] Why are we so afraid to say died? Death is one of life's certainties, and we need to help people to approach it without being scared [...]”***

- Age Scotland Supporter, Survey Response

Third-sector organisations offer valuable support, resources and training for individuals to have these difficult conversations, and this must be acknowledged more within outcome 1. In June 2024, About Dementia hosted ‘Good life, good death, good grief’ to facilitate a taster session of their **‘End of Life Aid Skills for Everyone’ (EASE)** course for carers of people living with dementia. They also hosted a session for people living with dementia to see how the course could be adapted to suit their needs.

***“[The session was] well-attended and highlights the need for discussions around death, dying and bereavement as this is considered a taboo subject. The feedback we received from attendees highlights how beneficial the group found the session and the need for more discussions surrounding future care planning [...]”***

- Reflections from About Dementia staff following EASE Engagement sessions

These third-sector resources and training sessions must be funded sufficiently and sustainably for there to be a wide-reaching and lasting impact on people in Scotland to talk more openly and confidently about death.

Finally, conversations around death, dying and bereavement can only be talked about more openly if the media portrayal of incurable conditions, such as dementia are supportive of opening these conversations up. Media messaging must show that it is possible to live well with life-limiting conditions such as dementia and that talking openly about the future is crucial.

<sup>8</sup> The Alzheimer's Society of Ireland. *Opening Conversations. Developing a model for the Alzheimer Society of Ireland of best-practice palliative care interventions for people with dementia and their carers.* [Link](#)

<sup>9</sup> Yorganci, E., & Sleeman, K. E. (2023) *Palliative care can benefit people with dementia.* [Link](#)

<sup>10</sup> J. Koffman (2018) *Dementia and end of life care for black, Asian and minority ethnic communities.* [Link](#)

## Cultural awareness

To inform this response, we spoke with members of the **Scottish Ethnic Minority Older People Forum [SEMOPF]**.<sup>11</sup> Several points were raised around the understanding of palliative care and the provision of information:

- There is a lack of understanding of what palliative care is and how people know if they need it. There must be additional effort through this strategy to improve education for ethnic minority communities around what palliative care is and how it differs from end-of-life care. This must be done in an accessible and culturally appropriate way.
- There is often not a direct translation of the term ‘palliative care’ into other languages. Some members of the forum asked if the name ‘palliative care’ could be changed to something which translates better.
- There is not a one size fits all approach to improving understanding and being culturally respectful

***“We always shy away talking about death and avoid the subject. Medical staff should be honest, less use of complicated medical terminology, simple explanations, respectful of cultural differences, and [of] patients and families wishes.”***

**- Member of SEMOPF**

## Wider support and community networks

We agree with the importance of community networks in increasing understanding and awareness of palliative care. We have heard from people living with dementia that they feel there is a lack of information available to them in terms of palliative care, if they are eligible and where to get support. We ask that this outcome includes actions to ensure there is support and signposting to palliative care services through dementia meeting centres and dementia-friendly communities. Additionally, comments were raised about how palliative care charities, such as Marie Curie, are still thought to only support people living with cancer. Using existing networks of support to get information about palliative care, including where specialist support is available and to who, out to the community is essential for this outcome to be achieved. Crucially, these community support groups and networks, such as dementia meeting centres, must be provided with long-term, sufficient funding.

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<sup>11</sup> Age Scotland. Scottish Ethnic Minority Older People Forum. [Link](#)

**4. Do you agree with strategy outcome 2 and the proposed actions being developed to deliver this outcome? Please add any comments you have about outcome 2 and its actions here.**

## Agree

Outcome 2 must be clearer about the accountability mechanisms on those who are responsible for delivering the strategy. We are disappointed that this draft strategy does not provide clarity around responsibilities and accountability for delivering each action. We urge that stakeholders be given the opportunity to review and comment on the responsibility and accountability of each action ahead of the final strategy being published.

In relation to the proposed National Care Service Board (NCSB), as part of the National Care Service, we agree that this could be an opportunity to improve the delivery of palliative care in Scotland. However, given the delays to the process of establishing a National Care Service and the uncertainty which remains about what this will look like, or if it will even happen at all, the implementation and delivery of this strategy must not solely rely on a reformed social care system.

**5. Do you agree with strategy outcome 3 and the proposed actions being developed to deliver this outcome? Please add any comments you have about outcome 3 and its actions here.**

## Agree

We agree that leaders must have access to the relevant data to inform the planning and delivery of palliative care services. This must include data on the number of people requiring and accessing palliative care as well as local population data so that specific local needs can be understood, and targeted support provided. We recommend that this data be made publicly available as it would be useful for third-sector organisations including Age Scotland, to gain a better understanding of who is accessing palliative care.

It is important that when improving the quality of data around palliative care, the diagnosis someone receiving palliative care has received should be collected. This will help to create a picture of where most resource needs to be focused, as well as areas in which those who might be eligible for palliative care, are not receiving the support.

**6. Do you agree with strategy outcome 4 and the proposed actions being developed to deliver this outcome? Please add any comments you have about outcome 4 and its actions here.**

## Agree

One of our key asks is that the Scottish Government prioritise earlier dementia diagnosis. From our engagement, we know that it can sometimes take months or even years to receive a diagnosis of dementia. Early identification and diagnosis can change the type of

support that people living with dementia can receive. For example, following a social model to encourage people living with dementia to engage and connect with their local community, such as through meeting centres, is usually more effective if the diagnosis is received at an earlier stage. We agree that earlier identification of all conditions is essential so that everyone can receive palliative care at a time that enables them to live as well as possible.

***“I used to think dementia diagnosis was the end of the world but now we're like everyone else here, we are just getting on with it. With a little help from our friends”***

**- Person living with dementia**

The process of diagnosing many incurable conditions can be challenging and many individuals may put off seeking a diagnosis. A particular challenge when diagnosing dementia is that people can often mask their symptoms during medical appointments or deny anything is wrong. This makes receiving a timely diagnosis, and subsequent access to care and support more difficult. To address this, training for health and social care staff must be improved to increase understanding of the subtle signs of dementia, and how to identify if someone is masking. Additionally, health and social care staff, especially GPs, nurses and old-age psychiatrists, must receive more comprehensive training on who is eligible for palliative care and when. Without these key professionals having sufficient knowledge and understanding, many individuals living with incurable illnesses will continue to miss out on essential care and support.

Tools to identify palliative care needs have an important role. However, tools such as the SPICT, whilst they include dementia and neurological disease as examples of life-limiting conditions which might make someone eligible for palliative care, only outline the more advanced indicators of the condition. We would argue that if the Scottish Government are aiming through this strategy to identify adults eligible for palliative care earlier, then identification tools such as the SPICT must be updated to ensure that they reflect earlier indicators of incurable conditions.

## Understanding the needs of palliative care service users

Instead of the strategy stating that “*future care planning **may** begin with a palliative care review*”, it should instead clearly emphasise future care planning **should** begin with a palliative care review. This is especially important if someone has received a diagnosis of dementia. A palliative care review during future care planning sessions can help to highlight that dementia is a terminal illness meaning the individual can be eligible for palliative care either now or in the future.

As previously mentioned, we are disappointed that information is not presented within this draft strategy as to where the responsibility and accountability for actions, such as providing a palliative care review, will be placed. This must be included in the final strategy

## Addressing barriers for groups to access palliative care

We strongly agree with actions 4.5 and 4.9. However, the strategy needs to be more explicit in what some of these barriers are, how they will be addressed in a culturally sensitive way and how this will be measured.

From our engagement with the Scottish Ethnic Minority Older People Forum [SEMOPF], and previous discussions with Age Scotland's LGBTQ+ Scottish Older People's Network, we have insights into many of these barriers. For older people from the LGBTQ+ community, there often remains mistrust around accessing health and social care services due to the historical discrimination many LGBTQ+ individuals have faced, such as during the HIV/aids crisis. This can mean that these individuals are often more reluctant to seek out the help and support they are entitled to. To address this barrier, there should be some kind of marketing campaign that explicitly states that palliative care services support and include LGBTQ+ people. This must be backed up by staff from the LGBTQ+ community supporting the service where possible, or staff who have training accreditations working with queer patients and are genuine allies.

For older people from ethnic minority communities, we have heard of numerous barriers to accessing health and social care services which also apply to accessing palliative and end-of-life care. Firstly, communication is a key barrier which needs addressing. From those we engaged with, this was suggested to include not only clearer communication and information about what palliative care is and who is eligible but also around aspects such as visiting hours at hospitals/hospices. Additionally, language barriers often add further stress during already challenging circumstances. Members of SEMOPF asked that language should be kept as simple as possible to aid understanding.

Another barrier individuals from ethnic minority communities may experience when accessing palliative care is understanding and respect for cultural and religious practices. For example, in some cultures, having only female carers is important, however, this is often not considered given the existing pressures on staff numbers. Another example is that for South Asian patients, they tend to have more family visiting them (e.g., in hospital or hospice settings), to recite prayers and they may therefore need more private rooms to allow for this to take place without disturbance. Finally, for those who follow the Muslim faith, patients might not want their legs to face towards Mecca whilst they are sleeping. Whilst these details are important for patients and their families during palliative/end-of-life care, they might disrupt others, or not be taken as important considerations. To address these barriers, suggestions from members of the SEMOPF included better training on religious and cultural preferences for those delivering palliative care, as well as a messaging option, like the 'not all disabilities are visible', to show someone has cultural/religious requirements for their care.

Finally, members of SEMOPF noted that a barrier to accessing palliative care may be around the common assumption that those from ethnic minority communities are automatically looked after by their families. Members noted that family shouldn't be

relied on to provide care, especially if they have additional caring responsibilities or are still in employment.

These barriers and suggestions for how they could be addressed should be carefully considered. Further details should be added to the actions under outcome 4 including who is responsible for addressing certain barriers and how.

## **7. Do you agree with strategy outcome 5 and the proposed actions being developed to deliver this outcome? Please add any comments you have about outcome 5 and its actions here.**

### **Agree**

We agree with the use of the term ‘future’, rather than anticipatory or advanced care planning as this encompasses a wider range of areas of someone’s life that need consideration when planning for care in the future. As part of the future care planning (FCP) process, resources including Age Scotland’s Lifebook (available [here](#)), should be promoted. This provides a place for older people to collate essential information regardless of whether they are currently living with a life-limiting illness. We ask that this strategy prioritises the use of flexible future care plans. No disease trajectory is linear and therefore an initial FCP following a diagnosis may not be applicable further down the line. Those delivering FCP support must not be complacent that once a plan is made, that is a job done.

Future care planning is especially important for those who receive a dementia diagnosis and is one of the five key pillars of dementia post-diagnostic support (PDS).<sup>12</sup> As future care planning is a pillar of PDS, we argue that PDS should be viewed as a key component of palliative care for people living with dementia. Additionally, from our engagements, we are aware of the common assumption that following a dementia diagnosis, things that used to matter to someone no longer do. This is simply not the case. By ensuring that person-centred, high-quality FCP is offered to everyone receiving a dementia diagnosis, this support can help to ensure that what matters to that person remains at the centre of all decisions.

Future care planning is also extremely important for minority communities. There are many potential benefits of FCP for ethnic minority and LGBTQ+ communities including being able to state preferences around preferred pronouns, chosen family, cultural preferences and dietary requirements. However, ethnic minority communities often do not have the same understanding of what FCP is, especially if there is no direct translation into their native language. Therefore, this strategy must ensure that the actions outlined to improve the provision of FCP include increasing access and use of FCP support by marginalised communities. Whilst this is stated in action 5.5, there needs to be further

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<sup>12</sup> Alzheimer Scotland. *5 Pillar Model of Post Diagnostic Support*. [Link](#)

detail about how this will be done in a culturally appropriate way, as well as how this will be measured.

## Digitalisation and digital legacy planning

We strongly support the digitalisation of care plans as this will make it easier to share plans between teams in different settings. However, digital-first approaches can risk excluding older people. Therefore, offline options for accessing and reviewing FCPs should also be made available, and support should be provided to individuals who need help accessing digital platforms if required.

Finally, we note the reference to digital legacy planning in outcome 5. We understand digital legacy planning to be the plans around what is done with any available online content (someone's digital legacy), following their death.<sup>13</sup> Given the increased prevalence of digital content, including emails and social media accounts, it is important that planning for what happens to any digital legacy becomes central to the FCP process. As this is a relatively new concept, there is limited evidence of the experience of palliative care professionals in supporting individuals with this area of FCP.<sup>14</sup> We believe that this strategy could be a pivotal moment to raise awareness of digital legacy planning. This must include educating health and social care professionals and the public on what digital legacy planning is and why it is important. We suggest that this should be facilitated by NHS Education for Scotland (NES) and should include promoting earlier conversations about digital legacies.

## **8. Do you agree with strategy outcome 6 and the proposed actions being developed to deliver this outcome? Please add any comments you have about outcome 6 and its actions here.**

### **Agree**

We agree with outcome 6, especially as issues of anticipatory grief and bereavement can disproportionately affect older people, in turn potentially impacting their health. Whilst it might seem like a normal part of ageing to experience grief and bereavement, this doesn't mean that older people should not receive the same support.

For outcome 6 to be achieved, there needs to be a greater understanding and respect for someone's individual beliefs, wishes, religious practices and cultural traditions as part of care around dying. From engaging with older ethnic minority people, communication around dying is important. Using complex medical jargon can be difficult for anyone but especially for those who English is not their first language. By not having information

<sup>13</sup> Stanley, S, Higginbotham, K, Finucane, A & Callistus Nwosu, A. (2023). A grounded theory study exploring palliative care healthcare professionals' experiences of managing digital legacy as part of advance care planning for people receiving palliative care. *Palliative Medicine*, vol. 37, no. 9, pp. 1424-1433. [Link](#)

<sup>14</sup> Ibid

communicated to them clearly in a way that they understand, experiences of anticipatory grief and bereavement can be worsened. To ensure this strategy improves experiences for everyone, this needs to be addressed via workforce training.

From our work with those caring for someone living with dementia, we often hear of the significant impact when they stop caring, either because the person they care for is taken into residential care or if they pass away. Whilst the strategy document mentions acknowledging the impact of caring for someone who is dying, we recommend that specific actions are outlined as to how those who stop caring are supported in this transition, for example through peer-support groups.

**9. Do you agree with strategy outcome 7 and the proposed actions being developed to deliver this outcome? Please add any comments you have about outcome 7 and its actions here.**

### Don't know

No comment – not relevant to Age Scotland's work.

**10. Do you agree with strategy outcome 8 and the proposed actions being developed to deliver this outcome? Please add any comments you have about outcome 8 and its actions here.**

### Agree

We agree it must be the responsibility of employers, professional bodies and education providers to ensure staff who deliver palliative care are appropriately trained and supported. This must be part of protected staff time to ensure that training is not seen as just a 'nice to do'. We ask that this training and support extend to those who are involved in the peripherals of care and support for those with life-limiting conditions. For example, those who provide support at dementia meeting centres/peer support groups. These people are often the vital link to signpost to other places of support and thus they too must be offered the same training.

We agree that staff should be aware of the available palliative care learning resources. However, further detail is needed as to how this will be managed as new resources are constantly being added, adapted or removed which is challenging to keep track of. We also ask that there be sufficient learning and resources around care and support for people living with dementia. We suggest that dementia awareness and inclusion training, such as the one offered by Age Scotland (more information can be found [here](#)), is provided to all staff who are involved in delivering palliative care.

## 11. Please add any further comments you have about the draft strategy outcomes and actions here

We broadly agree with the eight outcomes and corresponding actions within the draft strategy as they tend to cover the areas of palliative care in Scotland which need improvements. However, we have concerns about this strategy bringing about genuine change. As it stands, we echo other organisation's positions,<sup>15</sup> that the strategy outcomes are more like 'guiding principles' than tangible outcomes. The definition of an outcome is the 'activity, process or situation that exists at the end of it'.<sup>16</sup> Currently, the outcomes in the draft strategy are vague in terms of what will exist once the outcome has been achieved and are not measurable. For example, outcome 6 that the 'quality and experiences of care around dying and bereavement support are improved [...]' is ambiguous and doesn't provide clarity of what improved experiences would look like. The strategy outcomes should follow the **SMART principles**. 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 overall, more likely to create a measurable impact on experiences of palliative care in Scotland. Additionally, each action should include indicators which will be measured to demonstrate where changes have occurred. Outcome indicators can help to provide feedback on how the strategy is working, identify areas to change and create greater accountability,<sup>17</sup> something which the strategy as it currently stands is lacking.

The overall lack of detail of who will be responsible for delivering each action and how they will be held accountable is disappointing. We acknowledge that the strategy document states that this will be clarified in the final strategy. However, this should have been part of the draft strategy so that stakeholders, including those who may be responsible for certain actions, could have the opportunity to comment. Without clear responsibilities and sufficient accountability mechanisms, this strategy will not result in tangible change.

<sup>15</sup> Marie Curie (2025) *Response to Palliative Care Matters for All*

<sup>16</sup> Collins Dictionary. [Link](#)

<sup>17</sup> OECD Regional Development Working Papers (2016). *Using Outcome Indicators to Improve Policies: Methods, Design Strategies and Implementation*. [Link](#)

## Section C: Strategy content

**12. Community action and support - Do you think this strategy explains why it is important to encourage people, families and communities to come together, support each other, take action and talk more openly? Please add any comments you have about how to do this better in Scotland.**

**Yes**

For this to be improved in Scotland there must be longer-term funding for third-sector organisations that provide education and support for people and communities to talk more about death and dying. The current environment of short-term funding cycles creates uncertainty for organisations that help to support and improve the way we talk about and support each other during death and dying. This means that organisations cannot plan and often examples of good practice are not continued with funding moved elsewhere. This long-term issue requires long-term funding.

**13. Earlier access to palliative care - Do you think this strategy explains why getting palliative care long before someone is dying can help adults, children, their families and carers? Please add any comments you have about earlier access to palliative care here.**

**Yes**

We agree that the strategy explains why getting earlier access to palliative care is important. However, it needs to include a clearer explanation of who is eligible for palliative care. If people living with certain incurable conditions (e.g., dementia), are unaware they could be eligible for palliative care from the moment they receive their diagnosis, then earlier access for everyone will not be achieved. This must be addressed by improving public awareness and understanding, for example, through media campaigns.

**14. Improving access to palliative care and support - Do you think that the actions in this strategy can improve the experiences of people with different personal characteristics and circumstances? Please add any comments you have about impacts of the strategy on these or other groups of people here.**

**Unsure / Don't know**

To improve the experience of palliative care for people with different personal characteristics or circumstances there needs to be a clear definition of what equity means within the context of this strategy. Stating that the actions of the strategy will create more 'equitable access' to palliative care will make no difference if everyone, regardless of personal characteristics or circumstances, does not know what care they should expect to

receive. We reiterate our ask for the creation of ‘minimum service standards’ for palliative care.<sup>18</sup> This will ensure that everyone is aware of the minimum standard of care they should expect to receive, therefore defining what equitable access to palliative care looks like.

The actions in the strategy have the potential to positively impact older people if implemented in practice. Palliative care for older people living with an incurable condition can provide valuable support and improve their quality of life from the moment of diagnosis. However, there can sometimes be an assumption that having incurable conditions is an inevitable part of ageing which can prevent older people from accessing the support they need. This can especially be the case for people living with dementia, the majority of who are aged over 65, who may not know if palliative care is appropriate for them. We feel that this strategy’s actions could help to positively impact older people by improving understanding and awareness of palliative care services. However, for this to happen, the strategy outcomes need to be made more concrete and measurable, rather than ambiguous as is currently the case.

Finally, the strategy could positively impact marginalised groups including ethnic minority groups and members of the LGBTQ+ community, if their views and recommendations are taken on board. Whilst the strategy acknowledges that these groups may face barriers to accessing palliative care, there needs to be greater detail as to what the specific barriers are, how they will be addressed and who will be responsible for actioning these.

**15. Language and terms used in the strategy - Do you think the strategy explains what is meant by the terms palliative care for adults; palliative care for children; care around dying; and future care planning? Please add any further comments you have about any of the terms that are used in the draft strategy.**

**No**

We believe that the strategy does not fully explain what is meant by the term palliative care for adults. There is no mention within the explanation that palliative care is for those with an incurable or life-threatening illness which is likely to cause their death. Additionally, there is no reference to when palliative care is available, something which is commonly misunderstood. We would suggest that the explanation of palliative care for adults is adapted as follows:

*“Palliative care is holistic care **for anyone living with any progressive disease/illness which can reasonably be expected to cause their death.**<sup>19</sup> It prevents and relieves suffering through the early identification, assessment and management of pain and other problems*

<sup>18</sup> Age Scotland (2024). Right to Palliative Care (Scotland) Bill – Consultation response. [Link](#)

<sup>19</sup> **Note:** Definition of terminal illness is based on the Scottish Government’s definition for the purposes of accessing disability assistance. [Link](#)

– whether physical, mental, health, social or spiritual, **and is available as soon as a terminal diagnosis is received.**”

## Section D: Further Comments

### 16. Please add any other comments or suggestions you have about the draft Palliative Care Strategy here

Along with the concerns we have raised around the vagueness of the outcomes and the lack of clarity around the responsibility and accountability mechanisms for each action in the strategy, it is unclear exactly what resources will be used to deliver this strategy. As is too often the case, the strategy offers a lot but without sufficient financial resources, improvements will not be seen. The final strategy should include a commitment to where the resources, both financial and workforce, will come from.

### Want to find out more?

As Scotland’s national charity supporting people over the age of 50, Age Scotland works to improve older people’s lives and promote their rights and interests. We aim to help people love later life, whatever their circumstances. We want Scotland to be the best place in the world to grow older.

Our Policy, Communications and Campaigns team research, analyse and comment on a wide range of public policy issues affecting older people in Scotland.

Our work is guided by the views and needs of older people themselves.

### Further information

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