Consultation Response

Right to Palliative Care (Scotland) Bill

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June 2024

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

We welcome the opportunity to respond to this proposal for a Member's Bill to give people of all ages in Scotland living with a terminal illness a legal right to palliative care. This response is submitted on behalf of Age Scotland and About Dementia.

To inform our response, we have engaged with both Age Scotland's wider supporter network and members of About Dementia, including people living with dementia and unpaid carers. This has included a short digital survey which received **468 responses** in the fortnight that the survey was open for.

About Dementia held a policy drop-in session in collaboration with Marie Curie, to inform members of the proposed Bill. Following the session, members were invited to participate in an engagement session with About Dementia. This involved responding to a series of questions, guided by the consultation, prompting discussion of their key thoughts and opinions of the proposed Bill. These views were collated and have formed the core of our response.

We would like to thank Marie Curie Scotland for sharing their expertise regarding this proposed Bill, with members of the About Dementia team attending several of their roundtable discussions surrounding the proposed Bill, which have helped to inform our response.

Engagement Summary:

Consultation Response

- Policy drop-in and engagement session with About Dementia Members (People living with dementia and unpaid carers), and stakeholders with 8 attendees present
- Online snap survey to Age Scotland supporters with **468 responses** received
- Participating and learning from two **round table discussions** surrounding a Right to Palliative care with **Marie Curie Scotland**

Recommendations:

- We **strongly support** a legal right to palliative care which should be implemented as a standalone act
- There should be improved **education and awareness** of what palliative care is and who is eligible. Particularly for conditions which are less commonly thought of as 'terminal', such as dementia
    - We recommend that this is considered by the strategy delivery group for the next delivery plan of the Scottish Government's new dementia strategy
- We recommend there is improved, **mandatory education and training** for healthcare professionals about palliative care and how to have open conversations about future care planning
- We strongly support the creation of **minimum service standards** for palliative care
- We recommend that a legal right uses and **builds upon existing frameworks,** such as post-diagnostic support for dementia
- There must be a **clear, accessible,** and **empowering definition** of palliative care, including a clear distinction with end-of-life care
    - We support the use of the **World Health Organisation definition** of palliative care but recommend some alterations to ensure the definition is inclusive and empowering for all
- We recommend following a **human-rights based approach** to involving people with lived experience in the policy development process, using the **PANEL principles**
- We recommend that integration authorities continue to have responsibility for delivering and implementing a right to palliative care

- We strongly recommend that **gaps in the provision** of services in Scotland are addressed. Most notably the lack of **admiral nurses** to help deliver dementia palliative care

- We strongly recommend that any greater responsibility placed on third-sector organisations is **sufficiently and sustainably funded** and resourced for a significant impact to be made and sustained long term

Question 1: Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care? Please explain the reasons for your response, including what you think a right to palliative care should deliver.

"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 […] Palliative care is not about dying, it's about being able to live your best, even though you won't be cured. You can be terminal for months, even years [...] As it stands, it is hit or miss whether people know about all that is available under the heading of palliative care. We need to make sure all who want to can access the most amazing things that are palliative care."

[Age Scotland Supporter, Survey Response]

We strongly agree that all terminally ill adults, children, and young people with a diagnosis of a life shortening illness in Scotland should have a legal right to palliative care. We believe that by introducing a legal right, this will help address the many existing inequalities in accessing good quality and timely palliative care in Scotland. As the national charity for older people, our response will be considering the need and potential impact for a right to palliative care for older people in Scotland (age 50+), and especially those living with a dementia diagnosis and unpaid carers.

From the snap survey carried out with Age Scotland supporters, there was an overwhelming support for the implementation of a legal right to palliative care in Scotland. Overall, **97%** responded 'yes'. Survey respondents were given the opportunity to explain their reasons for supporting or not supporting a legal right to palliative care in Scotland. From the qualitative responses provided, clear themes arose from the data.

Firstly, there was a common perception that everyone deserves to know they can get the support they need during later stages of life. Several respondents noted the importance of a legal right for someone who may not have the support networks around them to advocate on

their behalf. There were frequent comments relating to palliative care being a human right, related to a right for dignity throughout our lives and that this should extend up until death. As one respondent wrote:

"It is the same as any other care. Were we not promised care from the cradle to the grave?"

[Age Scotland Supporter, Survey Response]

We agree with this view that a right to palliative care is a human right and aligns with an overall right to health. The right to health entitles everyone to the *"highest attainable standard of physical and mental health,"* and is part of the International Covenant for Economic, Social and Cultural Rights (ICESCR).[1] The ICESCR is one of the four international human right treaties proposed to be introduced as part of the Human Rights Bill for Scotland, which is due to be scrutinised by the Scottish Parliament imminently.[2] As part of the incorporation of a right to health into Scots law, ensuring a right to palliative care following a diagnosis of a terminal illness, is as important as any other aspect of health. We believe that a sufficiently resourced and accessible palliative care service is crucial to realising this right in full.

Furthermore, several survey respondents noted their surprise that palliative care was not currently a legal right in Scotland. This was also reflected by a member of Age Scotland's Health and Wellbeing team's 'Experts Friends Panel.' They spoke of their experience with palliative care in England, which seemed part of the process of care following a terminal diagnosis and were shocked to hear this was not standard in Scotland.

In terms of when palliative care should be offered, as described in the policy intent of the proposed Bill, we believe that the right to palliative care should apply from the moment of a terminal illness diagnosis, whatever age this might be. The majority of the 468 survey respondents shared this view. When asked, '*Do you agree that a right to palliative care should apply from the moment of a diagnosis of a terminal illness?",* **72% of respondents selected 'strongly agree'**, and another 23% selected 'agree'. As evidenced in responses to our snap survey, we feel that the proposed right should be implemented in a manner that if palliative care is not accepted immediately after a diagnosis, regular check-ins and follow-ups should be scheduled to ensure that if people living with a terminal diagnosis change their minds, they are still able to access palliative care at any point during their journey.

"Support should be offered, it may not be taken at the time of offer but requested later when required in the process."

[Age Scotland Supporter, Survey Response]

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[1] World Health Organisation Website (2023). *Human Rights.* Link
[2] Scottish Government Website. *Human Rights.* Link

We believe that as suggested in the draft proposal, the right to palliative care should ideally be implemented as a standalone act. We feel that implementing the right as amendments to other pieces of Scottish Government legislation, such as the National Care Service or Human Rights Bill, whilst potentially relevant, could result in palliative care being an afterthought, and it not being implemented as successfully in practice. This is especially important given some of the concerns surrounding the implementation of the Scottish Human Rights Bill within the limitation of devolved competencies. [3]

Right to palliative care for people living with dementia

About Dementia's lived experience voices also strongly welcomed the proposal for a legal right to palliative care Bill to be introduced in Scotland during the engagement session. Of particular interest to note for the proposed Bill, is that there appears to often be a misconception that dementia is not a terminal illness. As one member living with dementia explained:

"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."

[About Dementia Member, Person Living with Dementia]

Whilst we acknowledge that dementia is cited as a terminal illness in the proposal document for this Bill, from speaking to people living with a dementia diagnosis and unpaid carers, it is apparent that even those people living with the condition often do not realise that this is considered a terminal illness. As such, this can, and will continue, to be a barrier to people living with dementia accessing the palliative care they are eligible for. About Dementia's members felt that a legal right to palliative care could benefit people living with dementia and unpaid carers if awareness that people living with dementia are eligible to this form of care is improved.

"I think a key thing would be that it's discussed. You know, I think people haven't realised that people die from dementia. People don't talk of dementia as a terminal illness. And actually, I've had arguments with people about it. You know, I've, I've said to people, dementia is the number one cause of death and people go, yeah, but people don't die from dementia. Well, yes, they do. But that is not in the public's realisation, I think it's something we should be talking about more and talking about more openly."

[About Dementia Member, Person Living with Dementia]

One of About Dementia's key messages is about advocating that people living with dementia can live full and fulfilling lives with their diagnosis, and that a dementia diagnosis does not

[3] Human Rights Consortium Scotland (2024). *The implications of the UNCRC (Incorporation) (Scotland) Bill Reference for the Scottish Human Rights Bill: A Paper by Professor Aileen McHarg.* Link

mean they are at the end of their life. We do not believe that talking about and improving access to palliative care contradicts this message. Conversely, based on discussions with our members, we believe that having a legal right to palliative care would positively impact people living with dementia and unpaid carers in Scotland. The support available through palliative care, including aspects such as symptom management throughout their dementia journey, would allow people with dementia to continue to live well and maintain full lives.

Evidently, there needs to be an effort to address this barrier for people living with dementia to access palliative care by increasing education and awareness about dementia as a terminal illness and what palliative care options are available. We would recommend that this is looked at within the next delivery plan of the Scottish Government's 10-year dementia strategy, 'Dementia in Scotland: Everyone's Story'.[4] With the initial delivery plan running from 2024 to 2026,[5] we believe that regardless of if the legal right to palliative care is implemented as a standalone bill, embedding a public awareness and education campaign around dementia and palliative care into the next strategy delivery plan would provide a good opportunity to address this barrier many people living with dementia face to accessing palliative care. This should be carefully considered by the strategy delivery group. We acknowledge the challenge of striking the right tone with this, given the sensitivity and taboo around discussing terminal illness and palliative care. However, with input from people with lived experience, we feel that addressing misconceptions surrounding dementia and palliative care as part of this government campaign could significantly help to raise awareness of the palliative care that people with a dementia diagnosis are entitled to. If the legal right is then also implemented, hopefully more people living with dementia, both now and in the future, will be able to exercise this right, with an improved understanding and awareness of what they are eligible for.

"Dementia isn't being as recognised as a palliative care need as other physical illnesses"

[About Dementia Member, Person Living with Dementia]

Linked to this lack of public knowledge and awareness of dementia as a terminal illness, and as such the eligibility for palliative care support, About Dementia members raised concern around the lack of education for healthcare professionals, and the common reluctance to have conversations surrounding future care planning and palliative care (including end-of-life care). Members felt that this is another key barrier which people living with dementia face to accessing palliative care and something which the proposed Bill for a legal right should address.

[4] Scottish Government (2023). *Dementia in Scotland: Everyone's Story.* Link
[5] Scottish Government (2024). *Dementia in Scotland: Everyone's Story Delivery Plan 2024-2026.* Link

"[Palliative Care] is never really spoken about with people at the start of dementia, it was certainly never discussed to me. I just assumed it would go on and it'd be dealt with right at the end."

[About Dementia Member, Unpaid Carer]

With conversations put off until later stages of the dementia journey, people living with dementia and their carers are commonly missing out on eligible support, with carers left to take on the responsibility of finding out about palliative care, including end-of-life care. About Dementia members recognised that this is a sensitive topic to discuss, especially during the earlier stages following a dementia diagnosis, when speaking about challenges that they are not yet facing may feel distant and abstract. However, we believe it is vital that these conversations take place at a point in which the person being cared for can clearly understand and communicate their preferences for palliative care as their dementia progresses.

"It's very difficult speaking to people about [palliative care], 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."

[About Dementia Member, Unpaid Carer]

We would recommend that mandatory training and education is provided to all health care professionals around how to have more open conversations about palliative care and future care plans with people living with any terminal illness, but especially dementia. For example, healthcare professionals could be made more aware of the Supportive and Palliative Care Indicator Tool (SPICT™),[6] which can be used to help identify people with palliative care needs. Within the guidance for using SPICT, there is information on how to have future care planning conversations so awareness of this resource could be raised with health and social care staff. We believe that this increased education to healthcare professionals around future care planning conversations, including the right to palliative care, would help address this barrier faced by people living with dementia to accessing palliative care in the future.

Whilst we strongly support the proposal for a right to palliative care Bill to be introduced in Scotland in principle, we feel that greater detail is required within the proposed Bill, should it progress further, as to how the right will be implemented and the difference it is hoped the right will make. Using the example of dementia post-diagnostic support (PDS) in Scotland, since 2013 there has been a commitment from the Scottish Government for anyone receiving a dementia diagnosis to receive a minimum of 12 months PDS.[7] Despite the commitment on

[6] Supportive and Palliative Care Indicator Tool. Link
[7] Scotland's National Dementia Strategy: 2013-16. Link

paper, people in Scotland receiving this full year of PDS has never reached 50% of those entitled to it since its introduction over 10 years ago.[8] This example is just one demonstration of where a government commitment or right is significant on paper but does not translate to success in practice. We recognise that the issue of a statutory right not resolving all the challenges facing palliative care is acknowledged in the consultation document. Nonetheless, we would urge the proposal for a Bill to provide more explicit detail into how the right will be implemented and upheld in practice and the desired difference the right will make. We support the call for a Minimum Service Standards for palliative care, as explored in depth in Marie Curie Scotland's response to this consultation. We believe that incorporating these minimum service standards would help to ensure that the right is implemented and upheld in practice, creating accountability on the delivering bodies to ensure that a difference is made with the introduction of a legal right.

Finally, for a right to palliative care to be implemented successfully in Scotland, we would recommend using and framing the right within existing support. From the dementia perspective, this would involve utilising and improving the post-diagnostic (PDS), support system. In the SIGN (Scottish Intercollegiate Guidelines Network) guidelines for the assessment, diagnosis, care, and support for people with dementia and their carers, any form of dementia care is seen as palliative care, including post-diagnostic support (PDS).[9] During engagement with About Dementia members, when asked how they felt about this, there was a feeling of uncertainty as to if PDS should be considered as palliative care. It was felt that there should be aspects relating to palliative care, including earlier discussions of future care planning and end-of-life care, within the one-year PDS support; however, this is currently not felt to be happening. We would recommend that should a right to palliative care be created, there should be a simultaneous review of what is included within post-diagnostic support. This could align with one of the key deliverables in the new dementia strategy's delivery plan of commissioning an independent evaluation of PDS policy and delivery. [10] Additionally, for many of the minority who do manage to access 12 months of post-diagnostic support, it is common for them to receive no contact with any form of support following this until a crisis is reached, leaving many to struggle alone.[11]

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[8] Public Health Scotland (2024). *Dementia post-diagnostic support. Local Delivery Plan Standard; Figures to 2021/22.* Link

[9] Scottish Intercollegiate Guidelines Network (SIGN) (2023). *Assessment, diagnosis, care and support for people with dementia and their carers.* Link

[10] Scottish Government (2024). *Dementia in Scotland: Everyone's Story Delivery Plan 2024-2026.* Link

[11] About Dementia (Age Scotland) (2022). *New National Dementia Strategy Consultation Response.* Link

"The problem with the post-diagnostic support system is that you are talking about a year's support, which usually comes at the start of somebody's journey not towards the end. But actually, their support needs increase not decrease."

[About Dementia Member, Person Living with Dementia]

We believe that by improving awareness and access to palliative care for people living with dementia; by ensuring there is better understanding of what care individuals are eligible for, this could bridge the gap felt by many following the end of post-diagnostic support. If as suggested, there are improvements made to PDS to address the current deficits, such as ensuring there is a greater emphasis on future care planning, a PDS model could help enable a smoother transition from palliative to end of life care. As stated in Fox et al's (2023), paper, "*Effective end-of-life care is made possible by good post-diagnostic support in dementia"* (p. 10).[12] One way in which this could be achieved is by the introduction of admiral nurses in Scotland, as are currently in place across England, who could help enable a smooth transition between PDS, palliative and end of life care.

Question 2: What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care? Please explain the reasons for your response, and whether you think a different definition of palliative care should be considered for health and social care legislation, human rights legislation, and other forthcoming legislation that is relevant to how people may experience end of life.

For the most part, we would support the use of the World Health Organisation's definition of palliative care, as outlined in the consultation document. We particularly support the holistic nature of the definition with references to not only physical but also spiritual and psychosocial needs.

Firstly, we believe that it is important to emphasise the critical need for a clear and accessible definition of palliative care to be used as the basis for the legal right, and within any subsequent guidance, educational resources, and awareness campaigns. During engagement with About Dementia members, and within the roundtable discussions held by Marie Curie, it became evident that there is commonly a sense of confusion around what 'palliative care' truly is. When About Dementia members were asked what they associated with the term palliative care,

[12] Fox, S., et al (2023). *A comparison of four dementia palliative care services using the RE-AIM framework*. BMC geriatrics 23, 677. Link

responses showed that this type of care was perceived to be short-term care, only for people at the very end of their life.

"I've always thought of palliative care as being literally, you know, the days before somebody dies"

[About Dementia Member, Person Living with Dementia]

Therefore, it appears there is a common misconception that palliative care is synonymous with end-of-life care. We do not see this as true. As Marie Curie explains, *"end of life care is part of palliative care […] people often have palliative care for some time before getting end of life care".*[13] Additionally, via the discussions surrounding this proposed Bill, a common theme also arose around the importance of ensuring that there was a clear distinction between this proposed Bill for a right to palliative care and the Assisted Dying for Terminally Ill Adults (Scotland) Bill,[14] currently with the Scottish Parliament. Whilst for some individuals the difference between a right to palliative (including end-of-life) care and assisted dying may be clear, if introduced as a Bill, this distinction should be clarified to avoid any misunderstandings when it comes to deciding if this Bill should become legislation.

As well as a clear and accessible definition of what palliative care entails as part of the proposed Bill, based on our engagement with older people, people living with dementia and their unpaid carers, we would recommend that there is a focused effort to improve education and awareness of what palliative care is. There should be a particular focus on demystifying the fact that palliative care is not just at the end of someone's life, but in fact it can (and should be available), from the moment of a diagnosis of any terminal illness and can include aspects such as symptom management. We believe that having this knowledge to access the palliative care that people are eligible for at an earlier stage, could help to ensure there is less need for intensive end of life care. This is especially important for people receiving a diagnosis of dementia as without this understanding and awareness of what palliative care is, they may not benefit from the support which is applicable to them. We would also urge guidance to be in-place, if this right is implemented as hoped, to ensure that health and social care professionals are clear about the definition of palliative care, who is eligible and what areas should be covered to ensure that palliative care is truly person-centred.

Returning to the World Health Organisation's (WHO) definition, as previously discussed, we believe that this should form the basis of a definition for palliative care, as has been used in England for implementing the legal right. About Dementia's lived experience voices supported the WHO definition. They particularly liked that the definition highlights the impact of terminal

[13] Marie Curie Website. *What is end of life care?* Link
[14] Scottish Parliament (2024) *Assisted Dying for Terminally Ill Adults (Scotland) Bill*. Link

illnesses on families and that palliative care should improve the quality of life for both the person with the diagnosis and their support networks. As one member stated:

"What I love about [the WHO definition], is it's actually bringing in the families, because if someone is at end of life, no matter whether it's three years down the road, five years, or next week, the families seem to get missed out in it, but it's the families that have been at the brunt of it the whole time."

[About Dementia Member, Unpaid Carer]

Additionally, from our engagement, members living with dementia and unpaid carers were pleased that the definition refers to not only the management of physical symptoms, but also emotional, psychosocial, and spiritual impacts of a terminal diagnosis.

Whilst we believe that the WHO definition provides a strong catalyst for creating a definition of palliative care in Scotland, we would put forward some suggested alterations to the definition for it to be used as the basis for the legal right.

Firstly, the use of the term "patient," potentially creates negative connotations of an individual who is at the mercy of an illness, rather than someone who has rights, choices, and freedoms both within their medical journey and their wider life. Instead, we support the suggestion from The Alliance's consultation response,[15] to replace patients with either simply "people" or even "people with a diagnosis of a terminal illness." This would ensure that people receiving a diagnosis of a terminal illness, such as dementia, feel they would be empowered in their position as someone with a diagnosis throughout a palliative care journey, and not dehumanised in the way that many feel from the use of the term 'patient.' We believe that the empowerment to live a fulfilling and complete life with a terminal diagnosis starts from the initial definition. We would also suggest adding a specific mention of unpaid carers following the acknowledgement of families, as it is not always family members who are impacted by a diagnosis of a terminal illness such as dementia.

Furthermore, we would also recommend that the word "suffering" within the WHO definition is replaced by something less subjective. Whilst palliative care is about caring for someone with a terminal illness, we feel that suggesting they will suffer could also add to feelings of disempowerment and may deter individuals from accessing the support they require. This is especially true for people living with a dementia diagnosis which itself is often misunderstood as a condition. Instead, simply stating that *"[palliative care] prevents and relieves pain and*

[15] Health and Social Care Alliance Scotland (2024). *Proposed Right to Palliative Care Bill consultation response.* Link

symptoms through the early identification …," would ensure the definition of palliative care is more accessible and empowering to those individuals receiving a terminal diagnosis.

Finally, as discussed above, there is a common misunderstanding about the difference between palliative care broadly, and where the specifics of end-of-life care fit into this. Based on our engagement with About Dementia members and wider Age Scotland supporter's, we would recommend including end of life care as part of the definition of palliative care, as considering them separately could create greater misunderstanding. From the snap survey carried out with Age Scotland's external supporters, **64%** felt that end of life care should be part of the definition of palliative care.

Using these suggested amendments, the WHO definition could be altered to create a definition of palliative care as the basis of a legal right in Scotland reading as follows: [16]

"Palliative care is an approach that improves the quality of life of [people] of all ages, their families [and unpaid carers] who are facing problems associated with life-threatening illness. It prevents and relieves [pain and symptoms] through the 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.]"

Question 3: Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings). What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness(es)? Please explain the reasons for your answer, including the impact this proposal could have on particular people if it became law, and if there are any ways you think the proposal could avoid negative impacts on particular people.

As the national charity for older people in Scotland, we are constantly working to ensure that older people have equitable access to the services and care they are eligible for. With the greatest demand in palliative care by 2040 expected to be in people aged over 85,[17] it is crucial that older people in Scotland are all able to equally access the support they need. We believe that implementing a legal right to palliative care in Scotland would have an overall positive

[16] Note: suggested amendments are stated in [closed brackets]

[17] Finucane, A. M., et al (2021). *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.* BMJ Open. Link

impact on people living with a terminal illness diagnosis, especially for those with protected characteristics such as older people and those with caring responsibilities. With a legal right, comes statutory duties and we believe that accountability on those providing palliative care services to comply, could contribute to progressing equitable access to palliative care.

We feel that the proposal document comprehensively recognises groups who currently face inequalities in accessing palliative care. We particularly note the emphasis of the "inverse care law" on groups including older people, ethnic minorities, LGBTQ+, people with disabilities and those living in rural and island communities. Additional details could be added to the proposal, for instance, around the cultural challenges which members of ethnic minority communities might face when it comes to accessing their right to palliative care, [18] and the barriers for those who identify as LGBTQ+.[19] We would again recommend that the cultural differences and beliefs of different communities in Scotland are considered during any awareness campaign around palliative care, as has been recommended in response to question 1.

Whilst we perceive a legal right to palliative care being implemented in Scotland to have a positive impact, precautions must still be considered to ensure that negative impacts on certain groups are avoided. For example, it will be important to ensure that all information surrounding the implementation of a legal right, awareness campaigns and resources relating to the right are accessible for all. This should include non-digital access, to avoid digitally excluding some older people and those in remote communities; translated information for those who English is not their first language and accessible formats including easy-read, brail and BSL (British Sign Language) where applicable.

Another area in which a legal right to palliative care must avoid increasing disparity is within the rural and island communities in Scotland. With a greater ageing population in rural areas, it is these communities who are likely to have increasing need for palliative care.[20] As has been widely discussed, people with a terminal illness diagnosis living in the more rural areas of Scotland face more challenges to accessing palliative care services, including a lack of public transport, and limited specialised services and out of hours support.[21] As is so often the case, urban-centric models of care are simply applied to rural settings which have very different needs. Therefore, we strongly agree with and support the proposal document emphasising the need for a right to palliative care to be equity informed. We believe that by creating a legal

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[18] Givler, A., Bhatt, H., & Maani-Fogelman, P.A. (2023). *The Importance of Cultural Competence in Pain and Palliative Care*. Link

[19] Jerwood, J., Allen, G., Juffs, H., Humphries-Massey, C., Wakefield, D., Hudson, S., Baron, L., Burgess, S., Kane, E., Simpson, K., Maxwell, P. and Brown, C. (2024) 'It's more than rainbows in receptions' – Working with LGBTQ+ People in Palliative and End-of-life Care. Link

[20] Finucane, A. M., et al (2021). *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.* BMJ Open. Link

[21] Marie Curie. *Accessing quality care in rural areas*. Link

right with minimum service standards and services being informed by local need, this can create more equitable access to high quality palliative care regardless of location.

Furthermore, a potential issue raised by a member of Age Scotland's Health and Wellbeing Expert Friends Panel, was around the potential negative impact on other areas of care, should a legal right to palliative care be implemented in Scotland. The concern was raised if the funding for palliative care would be taken at the detriment of other vital care services. Whilst we are fully aware of the constraints facing health and social care in Scotland, both in terms of funding and resources, we would hope that the Scottish Government would see the importance of providing sufficient and equitable access to palliative care to all those who are eligible via sustainable funding, whilst not negatively impacting other areas of care. Additionally, we believe that sustainably funding a strong palliative care service in Scotland is a preventative strategy, leading to less emergency hospital and intensive end of life care requirements.

Finally, we strongly agree with, and encourage the involvement of people with lived experience throughout the development and implementation of the policy, as stated in the consultation document. Through our own work, we have highlighted and campaigned for the meaningful involvement of people with lived experience through the entire policy process, from implementation through to evaluation. One significant example of this was our contribution to the development of the new national dementia strategy.[22] To inform our response to the strategy consultation, we carried out extensive engagement across Scotland at the end of 2022, speaking to people living with dementia, unpaid carers, and third-sector professionals.[23] Our response along with others helped to significantly shape the final strategy, ensuring that the voice of those with lived experience was embedded throughout. Furthermore, lived experience continues to contribute to the governance and oversight of the strategy as well as the production of the anti-stigma public campaign. [24] We believe that developing a right to palliative care should actively and meaningfully involve people with a terminal illness (covering a range of conditions including cancer, dementia, motor neurone disease etc), unpaid carers, families and health and social care professionals. It is critical that there is a strong feedback loop as part of lived experience participation, to ensure that participants feel they are meaningfully involved and that their contributions are not being used as a tokenistic 'tick-box' exercise as is commonly experienced. As such, we would urge for a human rights-based approach when involving people with lived experience in the policy process. This should follow

[22] Scottish Government (2023). *Dementia in Scotland: Everyone's Story.* Link
[23] About Dementia (Age Scotland) (2022). *New National Dementia Strategy Consultation Response.* Link
[24] Scottish Government (2024). *Dementia in Scotland: Everyone's Story Delivery Plan 2024-2026.* Link

the PANEL principles; Participation, Accountability, Non-discrimination and equality, Empowerment and Legality.[25]

Question 4: What is your view on how a right to palliative care should be implemented? For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented. Please explain the reasons for your response.

From our work across health and social care policy in Scotland, we are acutely aware of the current challenges and uncertainty surrounding the provision of health and social care. With the National Care Service currently under consideration, and the existing uncertainties around what this could look like, it is a challenging time in which to suggest how a new legal right to palliative care should be implemented. Despite this uncertainty, we would suggest that integration authorities continue to be responsible for palliative care, as is currently the case should they remain as they are within the existing health and social care infrastructure. This view was echoed by About Dementia members during our engagement:

"The way the structure is, yes, because that is the route to get to those services, there isn't another route to get those services unless you go privately and go down the self-directed support and you're buying that in for yourself"

[About Dementia Member, Unpaid Carer]

As the main accountable bodies, integration authorities should also be held responsible and liable for collecting and publishing information publicly on the number of people accessing palliative care, how and when this was offered and the experiences of those who have accessed it, as is suggested in the policy intent of the consultation document. We would also suggest that data is disaggregated by diagnosis, for example so that there is evidence of the number of people living with dementia receiving palliative care in Scotland each year. This would allow gaps in care to be identified and addressed to ensure that the right is being accessed equitably. Once again, we strongly support Marie Curie Scotland's call for minimum service standards for palliative care, which the integration authorities must follow to ensure there is equitable access to good quality palliative care across Scotland and to remove the existing 'postcode lottery' of care received. We believe that these minimum service standards should include details on standards of education for health and social care professionals, the quality of palliative care and how care should be governed and evaluated.

Alongside integration authorities delivering a right to palliative care overall, other organisations could also have an increased responsibility. An important gap existing in Scotland is the lack of

[25] Scottish Human Rights Commission. *A human rights-based approach: an introduction.* Link

specialist nursing staff for delivering palliative care for people living with dementia. In England and Wales, Dementia UK have developed and support a programme of Admiral Nurses across the country who provide specialised, expert guidance and support for people living with dementia, helping them to stay independent for longer, and supporting their carers.[26] Admiral nurses can also play a vital role in helping people living with dementia understand and access palliative care (including end-of-life care). According to Dementia UK, there are around 437 admiral nurses in England and Wales, in a range of community services, hospitals, care homes and hospices.[27] However, until recently, none of these were in Scotland. In 2023 in a significant step, the first admiral nurse in Scotland has been established in Orkney as a pilot, through a collaboration between Orkney Health and Care, Dementia UK, and Age Scotland Orkney. Whilst the impact of introducing an admiral nurse in Orkney is yet to be known, admiral nurses in England have shown to have positive impacts for those cared for,[28] providing more personalised care to enable individuals to live well independently at home into the later stages of their diagnosis. Given the evident impact of admiral nurses in the rest of the UK in supporting people living with dementia and their carers, including in relation to palliative care needs, we would recommend that, especially if the pilot in Orkney is found to be successful, this or a similar scheme should be implemented across Scotland. Whilst not taking the responsibility away from integration authorities, utilising existing evidence of good practice from other organisations could help to ensure that a right to palliative care is implemented successfully in practice, rather than simply being a right on paper. This could also extend to other aspects of palliative care, for example, by making use of existing expertise surrounding financial support such as financial advisors within citizen advice bureaus (CAB), could help with the implementation of the right. Importantly however, using existing organisations, especially from the third sector, to help implement the right to palliative care must be underpinned by appropriate funding and resources. Too often, additional work, as might be required should a right to palliative care be implemented into law, is delegated to third-sector organisations who struggle to deliver the requirements without sufficient and sustainable funding and resources.

Question 5: Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability? Please explain the reasons for your response.

[26] Dementia UK. *What is an Admiral Nurse and how can they help?* Link
[27] Dementia UK (2023) *Impact Report.* Link
[28] MacKillican, E., & Hills, M., (2024). *Creating a response hospice, Admiral nursing service to improve end of life care for patients living with dementia and their carers.* Link

As previously discussed, for the right to palliative care to be realised in practice and make the desired difference, the government must ensure that there is sufficient and sustainable funding dedicated to delivering palliative care equitably across Scotland. We believe that key to ensuring the successful implementation and delivery of the right will require collaborative, whole system partnership approaches to working between integration authorities, health, and social care providers and third sector and community organisations. As we have outlined, if the implementation of a legal right to palliative care will add additional pressure to existing organisations, it is unequivocally important that these are suitably resourced to deliver the necessary care.

Finally, a comment raised during the engagement carried out with About Dementia members was the belief that specific organisations which provide palliative care cannot be accessed by people living with dementia.

"Some of the barriers there is about knowledge […] I confess that I think of Marie Curie as an organisation which cares for people with cancer, I hadn't really tweaked that they do general end-of-life care"

[About Dementia Member, Person Living with Dementia]

As such, we would recommend that beyond the general need for education as to what palliative care is and who is eligible as has been discussed throughout this response, there needs to be further education from palliative care services and organisations to highlight and raise awareness of who can access services.

Want to find out more?

As Scotland's national charity supporting older people over the age of 50, Age Scotland works to improve older people's lives and promote their rights and interests. We want Scotland to be the best place in the world to grow older. About Dementia play a key role in this, working alongside people living with dementia, unpaid carers, and partner organisations to make a meaningful impact in influencing policy and practice.

Age Scotland's 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.