

The Health and Social Care Alliance Scotland (the ALLIANCE)

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Proposed Right to Palliative Care Bill consultation
ALLIANCE response

4 June 2024

Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to the consultation on the proposed Right to Palliative Care Bill. We consider accessible, high quality palliative care to be an essential component of the right to health and agree that it should be available to everyone who would benefit from it, for as long as they need it.

We recognise however that this is not currently the case, and that more must be done to expand palliative care provision for people living with life shortening and terminal conditions. A standalone Right to Palliative Care Bill may be one route to widening access, but as the consultation document itself notes, there are also possibilities to include the right within the current National Care Service Bill or upcoming Human Rights Bill.

Regardless of how this proposal is implemented, we recommend that the Scottish Parliament and Scottish Government prioritise improving the quality and availability of palliative care. Everybody deserves to be able to live a good life and have the best health possible, and this is particularly important for people living with life shortening or terminal conditions. And everyone deserves to be able to have a good death, in dignity and in a place they feel comfortable.

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.

Strongly agree.

The ALLIANCE strongly supports a human rights based approach to public service delivery and consider the right to palliative care to fit within the “right of everyone to the highest attainable standard of physical and mental health”. Also referred to simply as the right to health, this right is contained

within several international human rights treaties, including the International Covenant on Economic, Social and Cultural Rights (ICESCR)[1].

That the right to health is defined as the "highest attainable standard" is directly relevant to the proposed Bill. Whilst people living with life shortening or terminal conditions may experience an unavoidably lower standard of health than people without such conditions, they still have the right to the best health possible in the circumstances. Palliative care makes a significant and essential contribution to realising this right, including through helping people to alleviate symptoms, manage their condition, and improve their mental health.

Although the right to health is long established in international law, recent research commissioned by the ALLIANCE found that there was a lack of understanding of the right in Scotland, which impacted how services are accessed and delivered[2]. It is likely that this lack of understanding has contributed to the lack of consistency in planning for palliative care identified in the consultation document. A legal right to palliative care should be seen as both part of the progressive realisation, and as an opportunity to improve awareness, education and communication, of the right to health.

The lack of access to palliative care is having serious, negative consequences on many people's lives. The ALLIANCE have been engaging with one individual, whose case has also been featured through Marie Curie's 'Dying in the Margins' report[3], who has not been able to access palliative care. She has experienced issues including with pain and medication management, a lack of appropriate support from her GP, finding and affording food that she's able to manage with her conditions, access to social security, and a lack of support to help plan for her children's future.

Nobody should find themselves struggling so much as they approach the end of life. A right to palliative care should deliver the broadest possible access to available, appropriate, timely and good quality services and support for everyone who would benefit, regardless of where in Scotland

they live. It should also support people reaching the end of life who want to die at home to do so. This should include specific duties and obligations on Integration Authorities to plan for and deliver palliative care. Palliative care should be available at any point after someone has received a diagnosis of a terminal or life shortening condition, supporting them to live well and with the best health possible during that time, regardless of how long it may be.

Practical delivery of the right to palliative care should be aligned with other rights and duties that exist across the health and social care landscape. These would include current Scottish Government proposals such as the right to short breaks for unpaid carers, which would ensure that there is appropriate support both for unpaid carers and those they care for to access breaks and respite without disruption to palliative care.

Palliative care must also go beyond managing the direct symptoms and mental health challenges of life shortening and terminal conditions, to support people, as well as their unpaid carers, families and friends, to plan for the future. Living with a life shortening and terminal condition can be made significantly more distressing if people are worried about what will happen to their carers, family and friends after they die.

Whilst in some cases reassurance and compassion alone may help alleviate these concerns, at other times they may need support to make sure their affairs are in order. This might include help with legal matters such as their will and inheritance, financial matters like the beneficiaries of life insurance and pension schemes, and personal matters like making their wishes for their funeral clear.

Although the people providing the therapeutic aspects of palliative care cannot be expected to be able to directly assist with these issues, the palliative care system overall should be able to guide people through them. It should signpost people to the professionals best able to assist with any of these areas a person has identified that they need help with.

Similarly, the right to palliative care should be inclusive of support for those close to the person receiving it. Everyone who is preparing for or experiencing the loss of a loved one will naturally find the process difficult and upsetting, and therefore benefit from emotional, psychological and spiritual support. Some people will experience more complex grief which requires specialist bereavement counselling. Children and young people's services should recognise not only the differing needs of children compared to adults, but also the often very different experiences of grief following the death of a child.

As part of a human rights based approach, the right to palliative care should also have regard to key human rights instruments. The principle of the right to palliative care aligns well with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), with good quality palliative care likely to support the realisation of rights such as to independent living and equal participation in society. Provision of palliative care for children and young people should take account of their unique needs and evolving capacity over time and comply with the UN Convention on the Rights of the Child (UNCRC).

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?

The ALLIANCE broadly agree with the proposal to define palliative care with reference to the World Health Organisation's (WHO) definition. The reference in that definition to the "correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" is reasonably comprehensive, emphasising that palliative care must go beyond simply a person's physical health and into the wide range of things that may influence it.

We do however think that a formal definition of palliative care in Scotland should use slightly different wording to the WHO's definition, in order to be more easily understood and communicated. The word "psychosocial" for

example may be unfamiliar to many people, and the same principle could be conveyed by a phrase such as “physical, mental, social, environmental or spiritual”, which likewise emphasises there is more to the provision of palliative care than simply alleviating pain and other physical symptoms.

We also recognise the point made in the consultation paper that the terminology of “suffering” can be perceived in a very negative light. It may also encourage thinking of people living with life shortening and terminal conditions as unfortunate, disempowered victims, when the aim should be to empower people to live a good life and exercise choice and control over the circumstances of a good death. Participation in decision making is a key element of the right to health[4]. Similarly, the use of the word “patient” is often felt to be impersonal.

With the above points in mind, a slightly reformulated definition could be as follows [changes emphasised in square brackets]:

“Palliative care is an approach that improves the quality of life of [people] and their families who are facing problems associated with [life shortening and terminal illness]. It [supports people to enjoy the highest possible standard of health and wellbeing] through the early identification, correct assessment and treatment of pain and other problems, whether physical, [mental, social, environmental] or spiritual.”

This reworded definition is provided for illustrative purposes, rather than as an explicit recommendation for an exact definition.

Question 3: 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)?

In general, we would consider that a right to palliative care would have specific, positive impacts for disabled people, older people, and people living in rural areas. Most, if not all, life shortening and terminal conditions would generally be understood as disabilities, and therefore an enforceable

right to palliative care for people living with those conditions would naturally have a positive impact on disabled people.

Similarly, we know that as people age, they are more likely to develop diseases and conditions that can be life shortening or terminal, including cancer, dementia, and lung disease. Older people are therefore more likely to need to access palliative care, and to experience the gaps in provision that currently exist, and so to benefit from a right to palliative care.

As the consultation document notes, people living in rural areas are more likely to find it difficult to access palliative care. This can be due to a lack of provision in their area and the prohibitive costs of travelling elsewhere to access a service. A right to palliative care, accompanied by appropriate levels of resource, may help to increase the availability and affordability of palliative care for people living in rural areas.

Whilst we have identified some groups as being most likely to benefit from a right to palliative care, they will not be the only beneficiaries. Anyone may find themselves living with a life shortening or terminal condition, and therefore benefit from the right. Delivery of the right must however account for known and existing health inequalities, including greater prevalence of long term conditions amongst the least well off, and lower rates of accessing healthcare amongst ethnic minority groups.

We do not believe the right to palliative care would have any negative impacts on any group.

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?

Accountability is a key element of the right to health[5] therefore we welcome the recognition that there is a need to appoint responsible bodies and ensure robust data-gathering. However, we acknowledge that there is still a

degree of uncertainty regarding the structure of health and social care services in Scotland whilst the National Care Service Bill is considered by the Scottish Parliament. This is especially true in relation to children and young people's services, as it is still unclear whether they will be included within the scope of the National Care Service (NCS). It is important that clarity is provided on this front as soon as possible, to ensure that any right to palliative care fully includes children and young people, and improves transitions to adult services that are currently often poorly managed. The exact bodies that would be responsible for delivering on a right to palliative care will depend on the outcome of that legislative process.

Under present arrangements however, we would suggest Integration Authorities should have ultimate responsibility for delivering palliative care. This would mean that NHS boards and local councils would be responsible for the direct implementation of the right to palliative care, whilst the Integration Joint Board (IJB) would have responsibility for strategic plans and commissioning strategies. Responsibility for budgets and how to spend them would be shared across NHS boards, local councils and IJBs.

At the institutional level, duties should be placed on the relevant authorities to make specific provision for palliative care in strategic plans and commissioning, whilst the bodies responsible for direct provision of health and social care services should have a duty to produce their own palliative care strategy. Where possible, plans and strategies should be developed in partnership with people with lived and living experience of life shortening and terminal conditions.

At the personal level, a palliative care plan should be provided for anyone who is diagnosed with a life shortening or terminal condition. Such plans should be created with the input of the person themselves, any carers, family or friends they wish to be involved, and the service providers responsible for delivery of palliative care to that person. It is important that a personalised approach is taken to palliative care, as a one size fits all approach will not work given the vast diversity in conditions, life circumstances and preferences between different individuals.

To ensure responsible bodies are living up to their duty to realise the right to palliative care, there must be effective, accessible and transparent complaints processes in place for people who do not feel their rights have been respected. These processes must be clearly signposted, and impartial support should be made available to help people navigate them. It may be appropriate as part of this to direct people to independent advice and advocacy services, who can help them take informed decisions or advocate on their behalf if they are unable to do so themselves.

Training and education for the workforce will also be essential to any right to palliative care. This should be part of education at all stages and in all areas of the health and social care workforce, equipping them for both the delivery of high quality palliative care as well as identification of people who would benefit from accessing it.

Delivery of the right to palliative care should also be monitored through robust, disaggregated data gathering and analysis. This should be used to help identify issues such as ongoing unmet need, challenges that are specific to a particular group of people, and any gaps in provision that need to be filled. In line with obligations towards the progressive realisation of the right to health, this data gathering should also be used to provide evidence that there is continuous improvement in the delivery and experience of palliative care.

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?

For any human right to be fully realised, not just the proposed right to palliative care, adequate resource must be dedicated to the services necessary to deliver it. Given the scale of unmet need that currently exists with relation to palliative care, the proposed Bill would almost certainly have some upfront costs associated with it.

However, it must be understood that current unmet need in palliative care has costs in and of itself. Where people's conditions are worsening because they have not been able to access good quality palliative care, they are likely to require access to acute interventions that can cost significantly more than palliative care would have.

Similarly, the costs of unnecessary hospitalisation for people who otherwise could have, and would have preferred to, die at home are likely to be significant. In that sense, a right to palliative care may reduce or at least reprofile existing expenditure in the long term, rather than simply representing an additional and competing ask for investment.

As Scotland has an ageing population, the level of need for palliative care will inevitably increase in the coming years. This should not be viewed as a negative or as a cost to society, but instead a natural and positive investment in every stage of a person's life. People living longer, and living longer with life shortening and terminal conditions, should mean that they get to spend more time doing the things they love, with the people they love. Palliative care is how we can ensure that is the case for everyone.

Whilst we consider palliative care to be an investment, we also recognise that at a time of significant pressure on public finances, parliamentarians may be concerned about committing to long term increases in expenditure. The ALLIANCE have consistently strongly advocated for a human rights budgeting approach[6], rooted in the progressive realisation of human rights, and particularly two key principles – "non-regression" and "maximum use of available resources".

The principle of "non-regression" requires governments to ensure that changes in spending do not negatively impact human rights, including the right to health. Meanwhile, the principle of "maximum use of available resources" requires government to ensure adequate funding is available to ensure the progressive realisation of human rights.

We would therefore encourage the Scottish Parliament and Scottish Government to develop an approach to taxation and revenue raising that is centred on securing the finances necessary to deliver on human rights duties and other key policy objectives such as climate change and poverty reduction. Were such an approach to be taken, alongside long term shifts in our approach to the economy such as through the wellbeing economy model, it would help to ensure sustainable funding for palliative care long into the future.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level.

The ALLIANCE has a strong and diverse membership of over 3,500 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by

informing national policy and campaigns, and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.

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[1] United Nations, Office of the High Commissioner for Human Rights, 'International Covenant on Economic, Social and Cultural Rights' (December 1966), available at: https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights

[2] The ALLIANCE, 'Investigating knowledge and understanding of the right to health' (December 2023), available at: https://www.alliance-scotland.org.uk/blog/news/new-report-investigating-knowledge-and-understanding-of-the-right-to-health/

[3] University of Glasgow and Marie Curie, 'Dying in the Margins' (2023), available at: https://www.gla.ac.uk/media/Media_1020538_smxx.pdf

[4] United Nations, Office of the High Commissioner for Human Rights, available at: https://www.ohchr.org/en/health

[5] As above

[6] The ALLIANCE, 'ALLIANCE budget briefing 2024-25 calls for investment in health, wellbeing and dignity' (December 2023), available at: https://www.alliance-scotland.org.uk/blog/news/alliance-budget-briefing-2024-25-calls-for-investment-in-health-wellbeing-and-dignity/