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?

 Strongly agree

Please explain the reasons for your response, including what you think a right to palliative care should deliver.

We strongly believe there should be a legal right to palliative care. Ensuring access to high-quality palliative care is crucially important for people living with a terminal illness like Motor Neuron Disease (MND). MND is a rapidly progressing terminal neurological illness, which stops signals from the brain reaching the muscles. This causes muscle weakness and wasting. MND can rob someone of the ability to walk, talk, swallow and breathe. The average life expectancy of someone with MND is just 18 months from diagnosis. There is no cure or meaningful treatments. While there remains no cure for MND, palliative care plays an essential role in managing and alleviating symptoms as well as maximising quality of life for people with MND.

Good palliative care involves taking a holistic approach to meet the comprehensive needs - physical, emotional, social and spiritual - of the person with MND and their loved ones. For people with MND, this includes support with communication aids, nutritional needs, respiratory care, psychological services and so much more. If wanted, people with terminal illnesses like MND should receive palliative care from the point of diagnosis. A right to palliative care should help ensure this happens. Advance care planning is crucial to ensure patients' wishes and autonomy remain central as the disease progresses.

Loved ones and carers of people with MND also require support through palliative care. Caring for someone with a terminal illness like MND can be emotionally and physically exhausting. Carers in Scotland play an invaluable role, and their own wellbeing needs must be prioritised with respite care, counselling and education on caring. The holistic nature of palliative care means supporting the family as well as the person with MND.

We believe these are the key elements of good palliative care for people with MND:

Focusing on quality of life

Palliative care is about physical, psychosocial, and spiritual care. This holistic approach allows patients to live as fully and comfortably as possible.

During a small focus group discussion which we facilitated last month, bereaved carers also noted that good palliative care should be holistic. This included when a person with MND needed essential home adaptations in place quickly. One of our participants was told by someone from their local authority that there would be no

point in getting a wet room because they "wouldn't live long enough" to benefit from it. Equally, others voiced concerns about whether using the term "palliative" would have a negative impact with potential obstacles being put in their way. They worried that local councils facing financial pressures would give people with terminal illnesses like MND less priority, not more.

It was also noted that the consultation paper on the right to palliative care didn't have details about the impact of not having good palliative care, and it was suggested that to make the case for why a right to palliative care is necessary, this would be important.

Respect for autonomy and patient wishes

A right to palliative care would enshrine the principle that patients' voices, values, and preferences remain central in decisions about their care, even as their condition progresses. Again, advance care planning is crucial for protecting their autonomy and ensuring the right care is in place when needed for this rapidly progressing disease.

It is also important for there to be a wider educational element so that people understand their rights around accessing palliative care and navigating the complex systems. One participant of ours said he and his wife were “pretty well-educated” and had no issue articulating their rights, and in some cases challenging them, however, not everyone would be able to do this. This shouldn’t be a barrier to access support and maximising your rights. The additional right to advocacy could be critical here.

Support for families and carers

Palliative care should extend beyond the terminally ill person to provide psychological, social, and practical support for loved ones and caregivers, who face tremendous physical and emotional stress. This person-centred model which looks at the individual and those around them is vital.

Equitable access across all settings

Enshrining palliative care as a right would require universal access and integration of these services across hospital settings and community based care at home. No one should be denied high-quality palliative care based on where they live or die.

Accountability and robust frameworks

A legal right would hold the government accountable for implementing robust strategies, policies and resourcing to ensure high-quality palliative care is available to all who need it. It is particularly important for someone living with MND to get access to the care they need, quickly.

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.

Here is a response with the language adjusted to be more UK-focused:

The World Health Organisation's definition of palliative care is a robust and widely recognised standard that could provide a strong foundation for enshrining a legal right to palliative care in Scotland.

The definition appropriately frames palliative care as a holistic approach aimed at relieving suffering and improving quality of life for both the terminally ill person and their loved ones. It highlights the need to address the full range of physical, emotional, social and spiritual needs through comprehensive interdisciplinary assessment and management.

However, while the WHO definition is a good starting point, there are elements which we believe are not explicitly captured in the definition, much of which was raised by our focus group participants:

1) Explicit affirmation of respect for patient autonomy and involvement in care planning decisions

2) Specifics around equitable access and integration of palliative services across all care settings - NHS Boards, community services, care homes and hospices.

3) The importance of provision of palliative care from the point of diagnosis for illnesses like MND.

4) Provision of psychosocial support for unpaid carers dealing with the responsibilities of caring for terminally ill family or friends.

5) The importance of preserving the individual's voice and decision-making power in palliative care as well as the need for advocacy to ensure individuals, and their carers, receive what they are entitled to.

6) Bereavement support should be incorporated into a right to palliative care to support family and friends who are coping with the emotional, financial and practical challenges associated with death, dying and bereavement.

In legislating for a right to palliative care, the WHO definition provides a strong foundation that could be a starting point. However, we believe the above points should be considered if there is a willingness to expand and strengthen the definition. When we asked our small focus group of bereaved carers what their views

were on the definition, they agreed it was a good starting point. However, they said that there were elements which were missing. One participant said the focus should be on 'maximising' one's life, not just improving the latter years of one's life. They also highlighted the importance of accessing a right to palliative care from the point of diagnosis, if that was what the individual wanted. Discussions were had around the importance of language. One group member said the word 'palliative' could be seen as a negative label because it can be associated with end-of-life. In the context of MND, following a diagnosis, there was a consensus that it should be introduced in conversations at the beginning so it can help with future care planning which would improve outcomes for people who receive this care and support.

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)?

 Strongly agree

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 already said, we strongly believe there should be a legal right to palliative care. In addition, when implementing this, it is crucial to consider the specific needs and potential impacts for people living with motor neuron disease (MND). A few key considerations are outlined below.

Seamless Integration of Care

Our focus group highlighted concerns that accessing palliative care might negatively impact on people with MND's ability to access other services such as adaptations to their home because they have a life-limiting illness. Government would need to ensure that this was not an unintended consequence of a right to palliative care.

Those with MND face compounding challenges from their terminal diagnosis as well as physical decline where people become more and more disabled. It is essential that their disability-related needs should not be overlooked but seamlessly integrated into their palliative care plan. One participant from our focus group who also works in

the care sector said everyone in the sector should receive palliative care training. Robust training is needed to ensure palliative care providers understand how to provide holistic and cohesive care addressing both their terminal diagnosis and their rapidly progressive disability. Close working with MND clinical nurse specialists, who have a wealth of knowledge and experience of symptom management and knowledge of disease progression, as well as charities supporting individuals such as MND Scotland, will be key to ensuring the care received is person centred. Co-ordination of palliative care services with different healthcare providers (e.g. GPs, specialist nurses, hospitals) as well as social care is essential.

During discussions with our focus group, different experiences were highlighted in which clinical professionals played a key role to ensure that the care and support which was needed was coordinated well. In one case, the GP was a vital support from diagnosis to death, while in another case the MND specialist nurse was critical because of their specific knowledge and understanding of MND. For a third person, a neurorehabilitation specialist went above and beyond to support the person with MND and their carer. This shows the importance of a multidisciplinary approach and that key clinicians play a vital role in delivering palliative care and support for people with MND.

Accessibility

As MND progresses, it impacts mobility, communication, and independence. Palliative care services must work with key partners such as local authorities to ensure they are fully accessible. For example, having the appropriate facilities, equipment, and home-based care options that accommodate wheelchairs, voice technology, home modifications, etc. This allows patients to maintain dignity and quality of life. Our focus group participants were also keen to emphasise the impact of having access to adequate housing and adaptations. They believed having the right equipment could play a part in delivering a key element of palliative care for people with MND which would improve their quality of life.

Our focus group also expressed concern about potential unequal access to palliative care services across different regions, particularly in remote and rural areas. Equity of access to palliative care is essential and postcode lotteries must be avoided at all costs.

Carer Support

Carers of those with MND take on tremendous physical and emotional stress. Respite care, psychological support services, and practical assistance should be a core part of the palliative care plan for this population to prevent carer burnout and to ensure that carers are central to providing palliative care at home

Person-centred Care and Proactive care planning

People with MND should be empowered to direct their own palliative care as much as possible through supported decision-making. Care pathways must be highly personalised based on the person’s mobility, communication needs, living situation

and preferences. Proactive advance care planning is essential as MND rapidly progresses.

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.

Our focus group voiced some concerns about implementation. They noted that any implementation that would see this right upheld would have to be adequately funded and resourced. There was some scepticism about existing rights not being upheld and how a right to palliative care would be any different. Citing bin collection as an example, they believed this had been redefined as a service which was "nice to have" but no longer "essential". Participants questioned if palliative care could risk being reduced in the future to plug financial gaps in budgets. A right to palliative care should make this less of a risk but sufficient funding is essential. Concerns were expressed about the delivery of existing social care and the pressures in this sector, which is currently under resourced. Our focus group emphasised that funding should target service delivery rather than infrastructure. Participants also suggested pilot testing new services before nationwide implementation.

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?

As noted in previous answers, there are concerns from our focus group about where the funding for introducing a right to palliative care would come from i.e. would it come from existing funding pots from social care, IJBs, or the NHS or would there be additional investment. We have also highlighted concerns about equity of service and long-term sustainability. That said, these concerns did not detract from the importance of a right to palliative care for people affected by MND.