

“RIGHT TO PALLIATIVE CARE”

Response from The Salvation Army

JUNE 4, 2024

THE SALVATION ARMY

The following response is submitted on behalf of The Salvation Army, which engages with people facing death in residential settings such as care homes and in society at large through its network of community churches (corps).

The submission was coordinated by the Scotland Office, based in Edinburgh. In preparing the response we consulted with the director of Older People's Services, the Public Affairs Unit, and an officer of The Salvation Army who is a qualified GP and works several days a week on secondment at a local practice.

In making this submission, I confirm that we have read and understood the privacy notice referred to on p. 29 of the consultation document.

The Salvation Army will be happy to respond to any questions arising from this response. We can be contacted via email at scotland@salvationarmy.org.uk or by telephone at 0131 440 9109.

1. Do you agree that terminally ill adults and young people with life shortening conditions residing in Scotland should have a right to palliative care?

The Salvation Army strongly agrees with this proposal.

The Salvation Army believes that every human being is created in the image and likeness of God and is therefore endowed with an inalienable dignity and worth which we are all called to recognise and honour in our individual and collective relationships with one another.

Addressing the issues of euthanasia, assisted suicide, and living wills, a Positional Statement issued by The Salvation Army in the UK includes the affirmation that "we are required to care for one another, not least when ministering to the ill and dying" (cf. https://www.salvationarmy.org.uk/sites/default/files/resources/2020-05/euthanasia_assisted_suicide_and_living_wills.pdf)

Providing palliative care to those who are approaching death is clearly one part of this duty of care which we owe one another, as concluded by a Positional Statement issued by The Salvation Army's international headquarters on euthanasia and assisted dying:

> *" Respect for the dignity of human life demands quality care for all persons at the end of their lives. The Salvation Army therefore promotes access to palliative services that provide holistic care (physical, emotional, psychological, social and spiritual) when there is no longer medical hope for a cure. Optimal pain control and the overall comfort of the individual should be the primary goals of this care" (41dc0810-5725-47a0-bdb6-6b466dc7066f_English+Euthanasia+and+assisted+suicide+IPS.pdf, p 5, point 2)*

A right to palliative care begins from the premise that dying is a natural part of life, and that everyone has the right to a "natural death", should they so choose. A right to palliative care should ensure that those approaching death are able to live life as fully as possible and have a "good" death.

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 definition from the World Health Organisation focusses on illness and does not recognise that dying is a natural part of life. This narrow focus risks marginalising older people who may not have a confirmed diagnosis of a terminal illness but are on a trajectory to a natural death and who need the same support as those with a terminal illness or life-limiting condition. Their needs may include symptom control, pain management, together with psychological and spiritual support as they confront death.

While the definition provided by the WHO allows a clearer definition of eligibility for palliative care, this leaves the older population at risk of being overlooked. The Salvation Army would therefore support a wider definition in terms of end-of-life support for all those approaching death.

The Salvation Army urges that any definition of palliative care should be holistic, and recognise the need for spiritual support to be included. People often find great comfort in faith as death approaches, in some cases considering and/or discovering solace in spirituality for the first time. It is therefore advisable that legislation and plans for providing palliative care should have space for the provision of chaplaincy services from all faith traditions and movements.

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)?

The potential inequalities are clearly identified in the consultation document (p. 15-16) under the umbrella of the "Inverse Care Law". The reasons why different groups do not access palliative care are varied, ranging from socio-economic deprivation and financial hardship to cultural factors which inhibit engagement and the fear of ostracism.

A right to palliative care would require local authorities and health boards to make provision for people disadvantaged by socio-economic deprivation and for rural and island communities. In the case of rural and island communities, sustainable models of provision would have to be identified and implemented.

In the case of groups whose access to palliative care is hindered by cultural stigmas, research may be required to fully understand the factors at work and how to respond to them. This may well be achieved by collaboration of local authorities and health boards with local communities and charities which address the specific needs of local communities and of marginalised groups.

The use of a single recognised palliative care and end of life package may prove useful in raising awareness of palliative care and access, and also enable providers of care (for instance, care homes) to manage people's care more effectively.

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 implemented.

The right to palliative care should be implemented through detailed stategic plans developed by local authorities and health boards, which carefully consider the palliative care needs of the local population, including any specific requirements relevant to the location.

There should be a duty to fund palliative care, with associated provision for such funding to be available to charitable organisations of proven experience and capacity in the provision of palliative care.

The plans should be a matter of public record and be scrutinised by an independent body such as the Care Inspectorate, which should also be given the authority to monitor palliative care provision and provide appropriate reporting and statistics to the government and the public.

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?

The Salvation Army applauds the framework and terminology of "living with" terminal illness, rather than "suffering from", which emphasizes the reality that those approaching death can still enjoy a high quality of life.

The Salvation Army recognizes that increased provision of, and access to, palliative care will benefit not only the individual who is approaching death but will also help their families and others who care for them.

However, the emphasis on terminal illness and life-limiting conditions means the consultation does not address those who are dying a "natural death" as a consequence of normal aging. The definition of palliative care should be given a wider scope to ensure their needs are also recognized and they receive the support that they will require.

Edinburgh
4th June 2024.