Response to Consultation regarding the proposal by Miles Briggs MSP for a Right to Palliative Care (Scotland) Bill

[redacted]

I request that this response be treated as anonymous.
I confirm that I have read and understood the privacy notice to this consultation, which explains how my personal data will be used.

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
Partially agree
Neutral (neither support nor oppose)
Partially disagree
Fully disagree
Unsure

Palliative care is an expression of the truly human attitude of taking care of one another, especially of those who suffer. It is a testimony that the human person is always precious, even if marked by illness and old age. Indeed, the person, under any circumstances, is an asset to him or her self and to others. This is why, when their life becomes very fragile and the end of their earthly existence approaches, we feel the responsibility to assist and accompany them in the best way.

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?

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.
Palliative care:

- includes prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs (whenever possible, these interventions must be evidence based);
- provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care;
- is applicable throughout the course of an illness, according to the patient's needs;
- is provided in conjunction with disease modifying therapies whenever needed;
- may positively influence the course of illness;
- intends neither to hasten nor to postpone death, affirms life, and recognises dying as a natural process;

- provides support to the family and the caregivers during the patient's illness, and in their own bereavement;
- is delivered recognising and respecting the cultural values and beliefs of the patient and the family;
- is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary);
- can be provided by professionals with basic palliative care training;
- requires specialist palliative care with a multi-professional team for referral of complex cases.

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
Partially agree
Neutral (neither support nor oppose)
Partially disagree
Fully disagree
Unsure

Any dying patient should receive the best possible comprehensive palliative care - physical, emotional, social, religious, and spiritual. The relatively new field in medicine of palliative care has made great advances and is capable of providing comprehensive and efficient support to dying patients and their families.
Palliative care should be promoted for the patient and for her/his family at the end of life. Palliative care must aim at achieving the best quality of life for patients suffering from an incurable and progressive illness, even when their illness cannot be cured, thus expressing the noble human devotion of taking care of one another, especially of those who suffer.

Whatever laws and policies protect the rights and dignity of the dying patient, in order to avoid euthanasia and foster palliative care, are to be commended.

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.

Palliative care services, provided by an organised and highly structured system for delivering care, are critical for realising the most ancient mission of medicine: "to care
even when there is no cure". Professionals and students ought to be encouraged to specialise in this field of medicine.

Validated and professional palliative care should be supported everywhere and for everyone. Even when efforts to continue staving off death seem unreasonably burdensome, we are morally duty-bound to provide comfort, effective pain and symptoms relief, companionship, care, and spiritual assistance to the dying patient and to her/his family.

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?

We, as a society, must assure that patients' desire not to be a burden does not inspire them the feeling of being useless and the subsequent unawareness of the value and dignity of their life, which deserves care and support until its natural end. We should commit to raising public awareness about palliative care through education and providing resources concerning treatments for the suffering and the dying.

Policy-makers must ensure that universal palliative care access is provided and integrated with disease-oriented treatment. There is strong evidence that the value of palliative care (benefits in the reduction of suffering and cost savings from unnecessary disease-oriented interventions) is increased when patients access palliative care early (integrated with disease-oriented treatment) rather than late (after the failure of disease-oriented treatment).