Please find my submission to the consultation on palliative care. I am responding as an individual, but as a recently retired children's palliative care nurse.

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 – not even sure why this is a question or why we need a law to provide it?

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?

I prefer this one: Add the ACT definition:

> 'palliative care is defined as an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and it focuses on enhancement of the quality of life for the child and support for the family. It includes the management of distressing symptoms, provision of respite, and care through death and bereavement' (ACT/RCPCH 2009)

You can change the word child to adult in this definition and it still works or you could just change it to person?

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)?

I am not sure I understand the question. There should not be an issue – it should be everyone's right to gold standard palliative care regardless of age, diagnosis or location of care (Home, Hospital or Hospice). Palliative care is a philosophy of care and not a location of care and it does not distinguish between somebodies age, gender, status or diagnosis…It also should address someone's 'Total Pain'.

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.

Palliative care should become everyone's business who works in health and social care. We have to demystify palliative care and we need to help professionals get over their fear of dying – they transfer this fear onto their client group.

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The public and professionals alike need to see the difference between Palliative Care and End-of-Life Care. The definition above makes it clear that palliative care should start at the point of diagnosis or recognition. End-of-life Care starts in the last days of life. You need to be very clear about what you are asking for in your Bill – they are two different stages.

Likewise, we need to demystify death and dying…

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.

The issue is delivering this outside of the central belt of Scotland. Where I live here in Orkney a home death can't be assured or safe. Folk living in the isles would have to go to our local hospital in Kirkwall, travel to Inverness for hospice care or get telephone advice on symptom management from the hospice in Aberdeen. This is why it must become everyone's business. It is not complicated.

If Liam McArthur's Bill becomes law I can see folk in the isles opting for an "assisted death" out of fear of being left in pain and who could blame them.

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