THE QUEEN'S
NURSING
INSTITUTE
SCOTLAND

Proposal for a Member's Bill for a Right to Palliative Care – QNIS response

The Queen's Nursing Institute Scotland is a charity that works with community nurses and midwives to help them build a fairer, kinder, healthier Scotland. We now have over 150 contemporary Queen's Nurses who work in many different roles across health and social care, including care home nursing, district nursing, and palliative care nursing.

In putting together our response, we have consulted with Queen's Nurses to ensure that their views have been taken into account.

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?***

We believe that all children and adults living in Scotland should have the right to palliative care from the point of diagnosis. Good palliative care is life affirming, improves quality of life, and increases life expectancy. Too many people in our communities are currently either never receiving palliative care or only when they are at end of life.

However, we believe that in order to enable everyone to be able to access this right then effective service redesign must be implemented, otherwise there will not be the capacity or resource to meet the demand.

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?***

We feel that the World Health Organisation definition of palliative care is a reasonable basis for a legal right to palliative care. However, consideration needs to be given to the use of words like life-threatening and suffering which may cause barriers to communication with patients.

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)?***

Any new law could have a positive impact on all individuals in our society but only if it is followed by sustainable resources and service redesign so that all individuals are granted direct access to palliative care regardless of diagnosis, age, sexuality, gender, race, or rurality.

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.*

The right to palliative care can only be implemented with a cohesive approach from health and social care, and third sector organisations. We heard from a cancer and palliative care nurse that she could not continue to give person centred care that has a positive impact on her patients, allowing them to live well until they die, without the valuable input of third sector services. Queen's Nurses tell us that they find the lack of joint working and communication between health and social care a barrier.

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 have a knowledgeable and skilled workforce in community nursing that is well placed to offer high quality person-centred palliative care.

However, these services are under resourced and very stretched and so there needs to be significant investment in both specialist and generalist palliative care services for legislation to have any positive impact.

We received the following additional comments from our consultation with Queen's Nurses:

- Within my role in a rural island we try to provide specialist palliative care to people with other illnesses. Referrals for patients with cancer continue to increase. I fear that the predicted continued increase in cancer referrals is already reducing our capacity to offer specialist palliative care to patients with other conditions.

- I do think that perhaps the time has come for a designated palliative care service alongside but separate to cancer services. This would ensure a dedicated service and also remove barriers to accessing palliative care as it would not be seen as care primarily for cancer patients and would also ensure capacity.

- End of life care should remain a part of palliative care as preparing patients and families for a good death is a vital part of palliative care. Having these discussions and hopefully equipping people to cope well with end of life when it comes allows them to live well now. However I do wish that there was not so much focus on end of life care as this also causes barriers and sometimes late referral.

For further information, please contact: Helen Reilly, Head of External Affairs; helen.reilly@qnis.org.uk; 07846267652

Data Protection

As an MSP, I must comply with the requirements of the General Data Protection Regulation (GDPR) and other data protection legislation which places certain obligations on me when I process personal data. As stated above, I will normally publish your response in full, together with your name, unless you request anonymity or ask for your response not to be published. I will not publish your signature or personal contact information. For this consultation, your response will be published by Marie Curie on their website.

Information on how I process your personal data is set out in my privacy notice, which can be found here https://www.milesbriggs.scot/right-to-palliative-care-consultation.

Please confirm that you have read the privacy notice by ticking the box below.

☒I confirm that I have read and understood the privacy notice (referred to above) to this consultation which explains how my personal data will be used.

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