Please find attached a response to your consultation on the Right to Palliative Care (Scotland) Bill from the Free Church of Scotland.

The Free Church of Scotland is a Christian church with a network of around 110 congregations all across Scotland and over 12,000 of us gather at services every week to worship God, but our Christian faith affects all of our life, not just a Sunday at church. Our ministers and others are regularly involved in pastoral care which includes end of life care. We also have a number of members who work in care sectors, and we have drawn on their experience in preparing our response to this consultation. The response is approved by our Public Engagement Group, following consultation with Presbyteries and Boards.

Thank you for your work in bringing forward these proposals.

Kinds Regards,

Stephen

Stephen Allison

Minister, Kiltarlity Free Church

Assistant Clerk, Free Church of Scotland

Public Engagement Coordinator, Free Church of Scotland

Right to Palliative Care (Scotland) Bill

Response from the Free Church of Scotland

Consultation questions

Note: All answers to the questions in this section may be published (unless your response is “not for publication”).

Aim and approach

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?**

- [x] Strongly agree
- [ ] Partially agree
- [ ] Neutral (neither support nor oppose)
- [ ] Partially disagree
- [ ] Fully disagree
- [ ] Unsure

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

The Free Church of Scotland welcomes the proposed Right to Palliative Care (Scotland) Bill as an important step towards recognising the dignity and value of all in society. Scotland's Palliative Care services are world-leading, and staff involved do an extraordinary job, often going beyond their paid roles to provide care with the utmost compassion and dedication. This includes doctors, nurses and multi-disciplinary teams in general hospital wards, and GP surgeries, and Nursing Homes, as well as the specialist teams based in Hospices. However, Palliative Care is currently poorly resourced. Hospices have to raise around 60% of their funding by charitable giving. Many in Scotland tragically miss out on the excellent advances that have been made in palliative care and this is unacceptable. There is a need for much greater investment in palliative care for those facing death and support for their family and friends. A truly compassionate and just society would recognise that all life has intrinsic value and dignity – regardless of our circumstances. It would seek to do all that we can to care well for the whole person. Accordingly, we fully support the proposals to provide a right to palliative care to all who are residing in Scotland.

The experience of those involved in end-of-life care is that most care is excellent – physical suffering and other symptoms can be effectively addressed in up to 95% of patients, with appropriate medication, when treated by healthcare professionals with the relevant expertise. Scottish Palliative Care Guidelines are a helpful resource – the biggest challenge is proper resourcing of palliative care. The objective of improving end of life care could be achieved by increasing palliative care resources. In particular it would be helpful to ensure people can access the correct care without delay, no matter where in Scotland they might be based. More must also be done to deliver excellent palliative care in the community and this will require a greater investment in care provision.

We recognise that charitable giving is a great benefit, and many wish to donate to this work. However, the charitable giving ought to be an added extra, to provide additional services. The core of Palliative Care services should be fully-funded, to be available to all who need them, at the time of need, to a high standard. More funding should be provided for palliative care nurses who can help where patients are based further away from hospices. General nursing staff can also be given more training in relation to palliative care.

Currently Palliative Care specialist services tend to focus mainly on those with a cancer diagnosis, while far less support is available to those with other life-limiting diseases such as dementia or heart failure, because the resources are simply unavailable. A Right to Palliative Care should include all who are approaching the end of life and are in need of care, regardless of diagnosis.

There are occasional cases which are extremely complex and require expert input. Work should be done to ensure nurses have quick access to experts when things are not going well. It is also important to provide emotional and spiritual support to those facing a terminal diagnosis and their family and friends. It is vital that their fears are managed through providing clear information at an early stage of diagnosis and helping them to make a plan together. More work must also be done to educate the wider population on what is available in terms of palliative care and to encourage open conversations about dying, death and bereavement.

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.

   We do believe the World Health Organisation is helpful, however, we would like a greater focus on compassion in any definition proposed. The word 'compassion' comes from Latin and means 'suffering with' – walking alongside someone through suffering. This is key to any definition of palliative care.

   It is also vital that a holistic approach to palliative care is taken that recognises physical, mental, emotional and spiritual needs. There is often a lack of understanding in Scotland about what good spiritual care looks like – often it can become so generic as to not be helpful. Treating people with respect and dignity means engaging in some of the most important questions around death and what happens after death. It must be tailored to the individual. This requires spiritual input from chaplains and other religious leaders.

   Palliative care must also involve support for the whole family, not just the patient. This enables conversations to be had around bereavement and support to be given.

We recognise there are other aspects of palliative care such as financial support which can be hugely helpful. However, we also recognise that the burden of providing this kind of support could be unlimited and may not be practically deliverable by Government. In these circumstances we believe a definition should acknowledge these others practical aspects of palliative care as desirable but not include them within the definition for the purposes of the right to palliative care.

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)?

- [x] Strongly agree
- [ ] Partially agree
- [ ] Neutral (neither support nor oppose)
- [ ] Partially disagree
- [ ] Fully disagree
- [ ] Unsure

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.

Holistic palliative care must take account of all of a person's circumstances listed in question 3. We also believe some of these aspects currently disadvantage access to palliative care. This is most pronounced in terms of location and for our island communities but other factors can also have an impact. Accordingly, we believe a right to palliative care would have a positive impact on all of these groups as long as palliative care plans are tailored to individual's personal circumstances and palliative care is truly holistic – caring for physical, mental, emotional and spiritual needs.

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.

The duty must apply broadly across multiple different agencies including the NHS and local authorities. There should also be work done to establish centres of excellence that can provide support to all of Scotland.

We also believe there is an important role for chaplains and churches supporting the implementation of a right to palliative care.

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.

More work should be done to provide clear guidelines on what is appropriate palliative care to enable patients to understand their rights. There is also a need for an appeal body where patients who do not believe they are receiving the correct level of palliative care can go to. Any appeal system must be timeous due to the nature of end of life care. Monitoring should also be introduced to ensure excellent standards of palliative care, consistently applied, across all of Scotland.

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.

If a respondent is under 12 years of age, I will need contact you to ask your parent or guardian to confirm to us that they are happy for you to send us your views.

- ☐ Please tick this box if you are under 12 years of age.

I may also edit any part of your response which I think could identify a third party, unless that person has provided consent for me to publish it. If you wish me to publish information that could identify a third party, you should obtain that person's consent in writing and include it with your submission.

If you consider that your response may raise any other issues under the GDPR or other data protection legislation and wish to discuss this further, please contact me before you submit your response. Further information about data protection can be found at: www.ico.gov.uk.