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Submitted to Palliative Care Matters for All: strategy consultation
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Section A: Overall strategy

Question 1a Do you agree with the aims for this strategy?

Agree

Please add any comments you have about the strategy aims here.:

It is right and just that all adults and children should have the same access to well-coordinated, timely and high-quality palliative care, including much-needed support for families and carers, no matter where they live in Scotland.

Whatever their physical or psychological condition or age, human persons retain their dignity and are worthy of love, compassion, fairness and equity. This is true in a special way for those who are sick, including those affected by terminal illness and who are nearing the end of life. These people are to be met with compassion and supported in their difficulties and challenges, including the means to alleviate their suffering.

Palliative care constitutes a precious and crucial instrument in the care of patients during terminal illness. It is an authentic expression of human activity providing care and accompaniment and improving quality of life and wellbeing as much as possible and in a dignified manner. [https://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20200714_samaritanus-bonus_en.html]

However, there is a body of evidence which suggests that people across the UK are not receiving the palliative care that they need, when they need it. Research carried out by Marie Curie tragically reveals that one in four people in the UK die in these circumstances. [https://www.mariecurie.org.uk/media/press-releases/end-of-life-charity-marie-curie-reports-that-more-than-one-person-every-minute-will-die-with-palliative-care-

It is vital that civic authorities address this lack of care and commit themselves to extend palliative care to all people who need it and to assist them in the terminal stage of life.

Question 2a Do you agree with the strategy cornerstones, which form the basis for the strategy and delivery plans?

Agree

Question 2b: Please add any comments you have about the four strategy cornerstones here.:

It is crucial that the role of hospices, which are mostly charitable organisations, are fully recognised as integral to the health and social care systems when delivering palliative care, and they should be funded accordingly so that they can continue to deliver their services to as many people as possible in their local areas.

Section B: Strategy outcomes

Question 3a Do you agree with strategy outcome 1 and the proposed actions being developed to deliver this outcome?

Agree

Question 3b: Please add any comments you have about outcome 1 and its actions here.:

It is extremely important that all relevant and useful information about accessing a range of services is readily available and accessible through the NHS, the media, and local services, e.g. GPs, to ensure that patients, family and carers can get the care they need, when they require it, because of loss and bereavement.

Question 4a Do you agree with strategy outcome 2 and the proposed actions being developed to deliver this outcome?

Agree

Question 4b: Please add any comments you have about outcome 2 and its actions here.:

The provision of palliative care is an ideal example to illustrate the need for a consistent national approach with regards to funding and service delivery. It is crucial to have local and national oversight of services provided, to ensure equality of resources throughout Scotland. The proposed National Care Service must work effectively with the National Health Service to ensure that through care is provided.

Collaboration between key stakeholders is crucial for the improvement of palliative care services. A recent article by James Sanderson, CEO of Sue Ryder, puts forward a new model for future working between relevant agencies to improve services, including the creation of hospice wards on existing and new hospital sites. This, Mr Sanderson says, “will identify people in the last year of life in accident and emergency and other parts of the hospital. We can then transfer them into our specialist palliative wards that sit alongside the hospital. Immediately, we free up acute beds.”

“Once in our care”, he adds, “we can put packages in place to discharge people back to the community, helping contribute to the government’s vision and, crucially, helping people live the rest of their lives to the fullest, and in the place they most want to be – home.”

Mr Sanderson says that those who are unable to be discharged can remain in hospice care.
The full article can be accessed via this link: https://www.hsj.co.uk/we-need-hospice-wards-in-hospitals/7038344.article

Whilst we are not in a position to commend a specific model of end-of-life care, we do believe that it is important to consider all options for improvement, especially those put forward by experts in the field of palliative care.

Question 5a Do you agree with strategy outcome 3 and the proposed actions being developed to deliver this outcome?

Agree

Question 5b: Please add any comments you have about outcome 3 and its actions here.:

The collection and use of key data is crucial in ensuring an equitable approach nationwide. However, users of the services should always be given the opportunity to provide feedback on the services provided to ensure that the quality of provision is secured.

Question 6a Do you agree with strategy outcome 4 and the proposed actions being developed to deliver this outcome?

Agree

Question 6b: Please add any comments you have about outcome 4 and its actions here.:

Early detection of life-threatening illnesses is crucial so that plans can be put in place to ensure the best quality of life for patients and reassurance for their family and carers that everything is being done to assist their loved ones in whatever time they have left.

This, however, will have significant implications for the provision of funding and skilled personnel to ensure a consistent approach. This funding should not be entirely reliant on charitable contributions

Question 7a Do you agree with strategy outcome 5 and the proposed actions being developed to deliver this outcome?

Agree

Question 7b: Please add any comments you have about outcome 5 and its actions here.:

The provision of person-centred future care planning is essential, with care plans adapted to each individual, their circumstances, and their support mechanisms, including family and carers.

Question 8a Do you agree with strategy outcome 6 and the proposed actions being developed to deliver this outcome?

Agree

Question 8b: Please add any comments you have about outcome 6 and its actions here.:

A holistic approach is important around the quality and experiences of dying and bereavement care, ensuring that all involved, e.g. patients, health practitioners, families and carers, receive the care and support they need in challenging circumstances.

This must include spiritual assistance for patients and their families, provided by an appropriate faith leader such as a priest, minister, imam, or rabbi, when requested by the patient or their family.

Question 9a Do you agree with strategy outcome 7 and the proposed actions being developed to deliver this outcome?

Agree

Question 9b: Please add any comments you have about outcome 7 and its actions here.:

The distinctive needs of babies, children and young people living with serious health conditions should be fully recognised and addressed, so that the quality of their lives is enhanced by the palliative care given to them.

Adequate support must also be provided to families and carers as they face the significant challenge of a young person with a serious illness and all the emotional and psychological distress and heartache that this brings. This may include ensuring the provision of spiritual support from a faith leader such as a priest, minister, imam or rabbi.

Question 10a Do you agree with strategy outcome 8 and the proposed actions being developed to deliver this outcome?

Agree

Question 10b: Please add any comments you have about outcome 8 and its actions here.:

It is essential that staff who provide palliative care are supported professionally but also personally as they become involved in the lives of so many at such a critical stage of care.

Question 11 Please add any further comments you have about the draft strategy outcomes and actions here

Please add any further comments you have about the draft Strategy outcomes and actions here:

The draft strategy outcomes are the benchmark of good quality palliative care for those who are ill and for those who care for them.

It is important that the Scottish Government is firm in its commitment to ensuring that the aims of the strategy are met by 2030 at the latest. This, however, should not preclude the achievement of as many aims as possible prior to this date.

Section C: Strategy content

Question 12a Community action and support - Do you think this strategy explains why it is important to encourage people, families and communities to come together, support each other, take action and talk more openly?

Yes

Question 12b: Please add any comments you have about how to do this better in Scotland.:

Dying and loss are universal experiences affecting everyone. It is crucial that palliative care resources, including palliative care beds and palliative care professionals, are available throughout Scotland, including the ability to provide such care in patients' own homes to ensure they are surrounded by those they love in an environment they are comfortable in. No-one should be in a position where they feel that their life is not valued or that they are a burden.

Question 13a Earlier access to palliative care - Do you think this strategy explains why getting palliative care long before someone is dying can help adults, children, their families and carers?

Yes

Question 13b: Please add any comments you have about earlier access to palliative care here.:

More open discussion and promotion must take place about what is meant by palliative care. Those who have had relatives receive palliative care speak very highly of the care given by all the staff to their loved ones. However, there are still many people in our communities who have no experience or appreciation of the difference that such care can make for people to live the rest of their lives well, and how to go about receiving that care.

Question 14a Improving access to palliative care and support - Do you think that the actions in this strategy can improve the experiences of people with different personal characteristics and circumstances?

Yes

Question 14b: Please add any comments you have about impacts of the strategy on these or other groups of people here.:

It is vital to ensure the consistent provision of palliative care, regardless of personal characteristics and circumstances.

Every human being is valuable and deserves dignity and respect, including at the end of life. Nobody in need should be left behind.

Question 15a Language and terms used in the strategy - Do you think the strategy explains what is meant by the terms palliative care for adults; palliative care for children; care around dying; and future care planning?

Yes

Question 15b: Please add any further comments you have about any of the terms that are used in the draft strategy.:

These terms and definitions should be made more widely known and, as a result, would aid more open discussion about terminal illnesses, death and dying, enabling people to discuss their futures. Palliative care, by definition, cares not just for the patient but supports their families throughout the process and beyond.

We believe it appropriate to state that this laudable proposal for a palliative care strategy stands in stark contrast to the dangerous Assisted Dying for Terminally Ill Adults (Scotland) Bill which seeks to legalise doctor-assisted suicide in Scotland, and which is currently being considered by the Scottish Parliament. Rather than being used to kill people, many of whom are vulnerable, public resources should be invested in helping people to live and to be more comfortable at the end of life, as outlined in this strategy.

It is telling that a poll of Scottish palliative care specialists in 2023 revealed that 75 per cent would not be willing to participate in any part of the assisted suicide process, and almost half (43 per cent) would resign if their organisation provided assisted suicide. [https://apmonline.org/wp-content/uploads/APM-Survey-of-AD-Impact-on-PC-FINAL.pdf]

Palliative care specialists need to be retained, and this can be supported with greater investment in end-of-life care and rejecting assisted suicide.

We are concerned that in countries where assisted suicide and/or euthanasia is legal, provision of palliative care has been compromised. For example, in British Columbia, Canada, hospices in receipt of majority state funding are required to offer euthanasia, and the health authority is forcing the closure of one hospice which refused. [https://carenotkilling.scot/future-impacts/]

Section D: Further Comments

Question 16 Please add any other comments or suggestions you have about the draft Palliative Care Strategy here

Please add any other comments or suggestions about the draft Palliative Care Strategy here:

The Bishops' Conference of Scotland supports this draft Palliative Care Strategy; a strategy which upholds the dignity of human life for those at the end of life and their families and carers.

About you

What is your name?

Name:
Anthony Horan

Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:
Bishops' Conference of Scotland

Further information about your organisation's response

Please add any additional context:

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

Do you consent to Scottish Government contacting you again in relation to this consultation exercise?

Yes

What is your email address?

Email:
ahoran@rcpolitics.org

I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Please enter comments here.:

Asking for additional information