BHF Scotland Response to Consultation by Miles Briggs MSP on a Right to Palliative Care (Scotland) Bill

June 2024

Introduction

BHF Scotland welcomes the opportunity to respond to this consultation on a Right to Palliative Care in Scotland. As the nation's leading heart charity, we currently fund more than £52 million of research into heart and circulatory diseases, and represent the 700,000 people living with one of these conditions in Scotland.

Palliative care is an essential part of the care provided to people affected by cardiovascular disease. Over 18,000 people die from one of these conditions each year, but we know that many people with chronic heart failure, vascular dementia or other cardiovascular conditions are not being offered palliative care.

BHF Scotland recognises the significant unmet need that exists for palliative care across Scotland and supports the principle that the care we provide to people who are dying is as important as the care we provide to those being born, and throughout their lives.

Regardless of how this proposal is implemented, we recommend that the Scottish Parliament and Scottish Government prioritise improving the quality and availability of palliative care. Everybody deserves to be able to live a good life and have the best health possible, and this is particularly important for people living with life shortening or terminal conditions. And everyone deserves to be able to have a good death, in dignity and in a place they feel comfortable.

BHF Scotland is a member of the Scottish Partnership for Palliative Care and refers to their response to further detail on the proposed bill in addition to those given here.

Heart Failure and Palliative Care

One condition within cardiovascular disease where greater priority around palliative care is needed is heart failure.

Hear failure is a life limiting condition that around 48,000 people are currently diagnosed with in Scotland[i]. This figure, however, only includes those diagnosed in Primary Care and estimates suggest that the figure is likely to be significantly higher[ii].

Additionally, due to an ageing population and increased survival from acute cardiac events, such as heart attacks, the burden of heart failure in Scotland is rising.

Currently, around half of those diagnosed with heart failure in the UK die within five years of their diagnosis. This means that for those affected by heart failure, it is important that their palliative care needs are addressed.

However, rates of palliative care in heart failure are known to be lower that other conditions, such as cancer. A 2018 study by National Confidential Enquiry into Patient Outcome and Death National Confidential Enquiry into Patient Outcome and Death of patients in England found that only 12.5% of people diagnosed with heart failure were known to specialist palliative care services before death[iii].

The need to improve palliative care for those affected by heart failure is well understood and there is work being undertaken to improve these services. The Caring Together Programme[iv], a partnership

programme from Marie Curie, the British Heart Foundation and NHS Greater Glasgow and Clyde sought to improve palliative care using integrated care models and an evaluation of the programme found that the programme improved symptoms, provided individual planning, and reduced hospital admissions.

Additionally, work led by Yvonne Millerick, Heart Failure Palliative Care Nurse Consultant Lecturer in NHS GG&C, has developed a meaningful conversation plan for people with heart failure[v]. This communication plan was developed to enable conversations with patients at an early stage that will enable improved end of life planning.

Despite this ongoing work, it is clear much more needs to be done to ensure that everyone with Heart Failure in Scotland can have their Palliative Care needs assessed and met.

Consultation Questions

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

BHF Scotland supports the principle of incorporating a right to palliative care into Scots law. We believe that over time such a law will improve the experiences of people living with serious illness, dying and bereavement in Scotland, through an improvement in the care they receive.

Legislating for a right to palliative care is not a panacea or a short-term fix. However, a legal right to palliative care could place a clear duty on public bodies to improve palliative care.

BHF Scotland also supports the inclusion Marie Curie's proposal for Minimum Service Standards for palliative care to create a duty to be commissioned by Integration Authorities or their successors.

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?

BHF Scotland broadly agrees with the proposal to define palliative care with reference to the World Health Organisation's (WHO) definition.

The definition considers the holistic needs of a terminally ill person - not just their health and social care service provision needs. It is also vital that bereavement sits alongside palliative care as part of this holistic approach, as multiple people experience bereavement while someone is dying (anticipatory grief) and after their death including family, friends and health and social care staff.

The WHO definition must be articulated clearly to ensure informed understanding, regulation and management for patients, families and workforce to improve quality of life. The Scottish Government, Integration Authorities, the NHS and Local Authorities would benefit from onboarding and disseminating more widespread public knowledge about palliative care.

Implementation of a right to palliative care should, therefore, include a duty on responsible bodies to communicate that a right to palliative care exists, what it means and what it includes- with specific focus on explaining palliative care to people affected by dying, death and bereavement, and the general public to improve death literacy and public perceptions of 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)?

As in other health and social care settings and services, inequities and inequalities impact on whether or not someone might receive the palliative and end of life support they need.

Deprivation, geography, gender, religion, ethnicity, sexuality, learning disability, diagnosis and age are all biological and social determinants that can have an impact on whether someone gets the care and support they need at the end of life.

Measures which aim to make general services more accessible and person-centred will help to address inequalities in palliative and end of life care – for example work currently being done under the banner of health literacy . However, there are also specific actions within the sphere of palliative and end of life care which can contribute to addressing inequalities.

The implementation of a right to palliative care would represent an opportunity to address current inequities at the end of life. Those bodies responsible for the planning, delivery and improvement of palliative care should prioritise specific action to improve outcomes for disadvantaged groups. This should include: identification of the needs, preferences and barriers experienced by specific groups; service redesign informed by the experiences of specific groups; staff training in the needs of different groups; ongoing monitoring of the outcomes and experiences of specific groups.

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 organisation and delivery of palliative care is complex and fragmented. Organisations involved in providing palliative care include general practice, care homes, care at home services, hospices, NHS 24, NHS specialist palliative care units, Scottish Ambulance Service, and both acute and community hospitals. In addition to the NHS substantial parts of palliative care are delivered by the Third Sector, the Independent Sector and local authorities.

Legal responsibility for the strategic commissioning of adult palliative care lies with Integration Authorities. Palliative and end of life care has a key role to play in addressing the quality, safety and resource challenges facing NHS Scotland and Integration Authorities, and contributing to national priorities and outcomes. High quality palliative care – delivered in a range of settings - can reduce inappropriate hospital admissions, reduce overtreatment, facilitate discharge, support people and their families in the community, promote person-centred care and shared decision making, and support wellbeing during whatever time remains.

Legislation is not a magic wand which can change things overnight. There will remain a need for strategies, plans, improvement programmes, investment, research and sustained institutional focus and effort over time. Partnership working, mutual respect and recognition between organisations and individuals will be at the heart of delivering person-centred palliative care as part of a person's right, and Health Boards' and Integration Authorities' duty.

To support this, there is a need for a nationally consistent, integrated and accessible social and health care record, accessible to all who are involved in direct care delivery for the right to palliative care. This is paramount for ensuring consistency in palliative care service design and delivery for those with a terminal illness and at end of life.

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 see the response by the Scottish Partnership for Palliative Care for further details and views on the bill

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[i] HF analysis of Public Health Scotland GP patient prevalence data 2018/19
[ii] Conrad, N; Judge, A, Tran, J et al. Temporal trends and patterns in heart failure incidence: a population-based study of 4 million individuals, The Lancet, 2018; 391, 10120 www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32520-5/fulltext?elsca1=tlpr
[iii] National Confidential Enquiry into Patient Outcome and Death, Acute Heart Failure: Failure to Function. Available at: https://www.ncepod.org.uk/2018ahf.html
[iv] Marie Curie, British Heart Foundation and NHS Greater Glasgow and Clyde, Better palliative and end of life care for patients with advanced heart failure: The caring together programme, available at https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/currentpartnerships/caring-together/caring-together-summary-report-2017.pdf,
[v] What Matters to You? Meaningful Conversation Plan. Available at: https://static1.squarespace.com/static/62416ca389785537abb9dea3/t/6397111f009b9e4376c847c3/1670844705657/What+Matters+Meaningful+Conversation+Plan+%28SINGLE+PAGES%29.pdf