



Royal College
of Nursing
Scotland

**RCN Scotland's response to Miles Briggs MSP's
consultation on the**

Proposed Right to Palliative Care (Scotland) Bill

04 June 2024

Introduction

The Royal College of Nursing (RCN) is the world's largest nursing union and professional body. It is the leading national and international authority in representing the nursing profession. We represent over half a million nurses, student nurses, midwives, nursing associates and nursing support workers in the UK and internationally.

The RCN has over 49,500 members in Scotland. We campaign on issues of concern to nursing staff and patients, influence health policy development and implementation, and promote excellence in nursing practice.

Background

The National Health Service was founded on the principles of providing a health service from cradle to grave. Currently, however, there is a significant unmet need for palliative care, which is largely provided for by the voluntary sector. This proposed Bill, from Miles Briggs MSP, would establish a legal right to palliative care and seek to provide equitable access to the palliative support.

Consultation questions and RCN Scotland responses

Q1 - 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?

RCN Scotland response:

Yes.

Those in need of palliative care should experience a service which is delivered in a timely and seamless manner, accessing care in a coordinated and compassionate way at the end of life. The NHS was established on the basis of providing healthcare from 'cradle to grave' and currently, as the consultation document identifies, not everyone who needs palliative care is able to access services.

RCN Scotland agrees that there is a real and urgent need to improve access to palliative care across Scotland and that in some parts of the country, there are insufficient services to support people at the end of their lives. With palliative care delivered by a range of organisations and in a range of settings, there is a need to ensure sufficient resourcing and staff are in place to meet the demand for palliative care. Nurses are seen by the public as being professional and accessible and are well placed to initiate discussions on bereavement and end of life care. Nurses, particularly specialist nurses, district nurses and practice nurses working in the community and primary care, are very likely to be the people

asked to provide the coordinated care of those who can benefit from palliative and end of life care. They are frequently the main link between the GP, local authority and the patient. These teams are currently under enormous pressure, with a vacancy rate in district nursing of nearly 7%.¹

RCN Scotland is therefore sympathetic to the proposals in the consultation document and recognises the problem the Bill is trying to address. Notwithstanding, we are less clear about the merits and impact of introducing a specific legal right to receive palliative care. We can see the logic in the argument that introducing a legal right would 'focus minds' in terms of the commissioning of services by integration authorities. However, as we have seen with other legal rights in healthcare (such as diagnosis and treatment waiting time targets), unless they are enforceable, they may not result in change. RCN Scotland is therefore less sure that the Bill will necessarily make the difference of ensuring that people who currently don't get palliative care, receive that care. The bigger picture of ensuring that we have sufficient resources to provide that service, is certainly more important than whether or not a legal right exists (though we accept that both issues complement each other).

RCN Scotland represents nursing staff working in a range of health and social care services. It is therefore important to be able to justify why a specific and separate legal right to receive palliative care is needed, in addition to the current 'right to the highest possible standard of physical and mental health' that applies to everyone in Scotland under the United Nations' International Covenant on Economic, Social and Cultural Rights.

Q2 - 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?

RCN Scotland response:

RCN Scotland agrees that the World Health Organisation definition is narrower and therefore probably the best basis for any legal right to palliative care. As the consultation points out, there remains a need to consider the wider, often non-clinical range of support that people and their families require as they approach the end of their lives. Often it is help with things like housing, access to services and social inclusion which can make a significant difference to a person towards the end of their life, as well as what is traditionally meant by palliative care.

The consultation suggests that the approach in England, namely the creation of a statutory duty to commission palliative care services, is a model which could be adopted in Scotland. However, during the passage of the Health and Care Act 2022, the Lords amendment² which implemented the legal right was debated.

During that debate, Lord Howarth of Newport pointed out that the amendment “leaves rather a lot of wriggle room” because it does not “make it clear that it will be an inescapable duty...to ensure that palliative and end-of-life care is a universal service.” He also expressed concern that without monitoring, reporting and enforcement of this legal right, there was a risk that the provision of palliative care will remain patchy. If a legal right is the approach adopted in Scotland, RCN Scotland therefore suggests that these points need to be addressed.

As well as a definition of palliative care, consideration also needs to be given on the location palliative care is accessed. The consultation suggests that a right to access palliative care will apply to multiple settings but is less clear about whether an individual has a right to access services in the place of their choice. A person-centred approach to palliative care would suggest that this choice is available to people, meaning consideration will be needed to ensure that the current variety of services is maintained. Currently people access palliative and end of life care in a range of settings (from hospitals, to hospices, care homes and private homes) and ensuring these services, which are provided by a range of organisations, are joined up and adequately resourced will remain a significant challenge. Work will need to be carried out to be able to plan and predict likely demand for services and the locations that people will choose to die and therefore receive palliative and end of life care.

Q3 - 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)?

RCN Scotland response:

As the consultation correctly points out, the ‘inverse care law’ applies to palliative care and individuals experiencing socio-economic deprivation, women, and those living in rural communities are some of the groups most severely affected. This must be considered when planning the financial implications of the Bill, as outlined in response to question 5.

Q4 - 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.

RCN Scotland response:

While legal responsibility for the delivery of palliative care would most likely fall to Integration Authorities, the actual delivery of palliative care services would continue to be

shared by multiple organisations in a complex landscape. Implementation of a right to palliative care would have to take cognisance of this and makes implementation, enforcement and monitoring of a right to palliative care more complex and challenging.

In order to be able to meet this legal right, integration authorities must have sufficient resources and there must be the workforce available to provide services. Consideration should therefore be given to, alongside a legal duty on Integration Authorities, establishing a duty on Scottish Ministers to ensure that they take all reasonable steps to ensure integration authorities are able to comply with their duty. An example of a similar approach, in relation to staffing levels in health and care services, can be seen in section 12IG of the National Health Service (Scotland) Act 1978 (as amended by section 4 of the Health and Care (Staffing) (Scotland) Act 2019).

Data collection will be key to be able to carry out robust workforce planning and must include data on both unmet need as well as implementation of the legal right to palliative care. Measuring unmet need is complex and, while we support the aim of tackling the challenges of measuring unmet need and addressing gaps based on the evidence, within the context of a legal right to palliative care, careful consideration would be required to ensure this is done well, fairly and consistently.

Workforce planning remains wholly inadequate across health and social care. As part of RCN Scotland's response to the National Care Service (Scotland) Bill, we have been calling for workforce planning to be given greater focus and for it to be made clear that the National Board is responsible for national workforce planning for NCS services. Given palliative care will continue to be provided in a range of settings which will form part of the National Care Service (including community health and social care), the workforce requirements of meeting a legal duty to provide palliative care will have to be a consideration of the NCS governance structures and, ultimately, for Scottish Ministers.

Q5 - Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability?

RCN Scotland response:

RCN Scotland is of the view that implementing this Bill will have significant financial implications, the extent of which are currently unclear. We know that there is unmet need when it comes to access to palliative care across Scotland. If this Bill has the desired effect, a significant number of people who don't currently receive palliative care, will have a legal right to do so.

As already explained, palliative care is currently provided by a range of services, all of which are facing serious challenges in terms of meeting current demand. A significant funding gap has also been identified in the charitable hospice sector³, with the sector struggling to meet rising staff costs.

If demand was to be increased, by the introduction of a legal right and more people therefore accessing palliative care, this would require additional investment both in terms of facilities but more urgently in terms of additional workforce. Existing teams and existing services simply cannot meet the requirements which will be established by this Bill. Extensive and detailed work will be required to establish the financial implications of the Bill, not least because insufficient data exists on unmet need.

RCN Scotland would also like to take this opportunity to raise a related issue which is of concern to our members. The management and use of controlled drugs, which include a range of palliative care medication, is currently reserved under the Scotland Act 1998 and is governed by the Misuse of Drugs Act 1971 and related regulations. The effect of this regime is that care homes in Scotland are required to apply for licences, for each type of controlled drug, from the Home Office to possess stocks, unless the care home is wholly or mainly maintained by a public authority out of public funds. In Scotland, as there is no legal difference between a care home with nursing and one without, this applies to all care homes in Scotland (unlike in the rest of the UK, where care homes with nursing have to meet fewer requirements to store controlled drugs). The consequence of the current situation is a delay in alleviation of symptoms and access to end of life care for care home residents, where around 20% of all deaths take place across the UK. This poses a risk of unnecessary suffering by the resident and distress to families and staff.

RCN members have today (4th June) passed a motion calling for RCN to lobby for a change in the law to allow for care homes to be able to store supplies of anticipatory palliative care drugs, at the 2024 RCN Congress. Noting that this is a reserved matter and therefore not an issue which this proposed Bill can alter, a change in the law would result in significant improvements in terms of access to palliative care for those in care homes in Scotland, which is obviously a central aim of this Bill and is therefore relevant to consideration by this consultation. During this debate, a number of RCN members spoke about the need to ensure sufficient safeguards and training of staff were put in place alongside any change in the law. RCN members also repeatedly called for improved access and availability of palliative care for residents of care homes and community settings.

References

¹ NHSScotland Workforce 31 December 2023, TURAS Data Intelligence, <https://turasdata.nhs.scot/data-and-reports/official-workforce-statistics/all-official-statistics-publications/05-march-2024-workforce/> (Accessed 04 June 2024)

² Health and Care Bill: Volume 819: debated on Tuesday 1 March 2022, House of Lords, <https://hansard.parliament.uk/lords/2022-03-01/debates/57BC7A73-56C3-4102-8743-FE985DF995E2/HealthAndCareBill> (Accessed 04 June 2024)

³ Hospices in Scotland facing a collective deficit of £16m in 2023/24, St Columba's Hospice Care, <https://stcolumbushospice.org.uk/news/hospices-in-scotland-facing-a-collective-deficit-of-%C2%A316-million#:~:text=On%20average%2C%20two%20thirds%20of,Health%20and%20Social%20Care%20Partnerships> (Accessed 04 June 2024)



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