


# National Carer Organisations response to Proposed Right to Palliative Care (Scotland) Bill

## Introduction

The National Carer Organisations welcome the opportunity to submit a response Proposed Right to Palliative Care (Scotland) Bill.

The National Carer Organisations are Carers Scotland, Carers Trust Scotland, the Coalition of Carers in Scotland, MECOPP, Shared Care Scotland, and the Scottish Young Carers Services Alliance. Together we have a shared vision that all Scotland's unpaid carers will feel valued, included, and supported as equal partners in the provision of care.

The National Carer Organisations aim to achieve this through the representation of unpaid carers and giving them a voice at a national level. We believe we can deliver more for unpaid carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to unpaid carers.

## Consultation questions and response

### 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.

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

It is widely recognised that Scotland has an aging population, which inevitably means in years to come more people will be dying, resulting in greater demand for social care and palliative care. Marie Curie research highlights that by 2040, up to 10,000 more people will need palliative and end of life care each year, a 20% increase[1]. It is also projected that by 2040 that the largest increase in palliative care need will be for those aged over 85, which will account for almost half (47%) of people with palliative care needs. This demand comes as the cost of living with a terminal illness is rapidly increasing, as is the cost of delivering palliative care. Marie Curie's research highlights that unmet need of palliative care leads to poorer physical and mental health, and financial outcomes for terminally ill people, their families and unpaid carers.

The National Carer Organisations strongly supports the Right to Palliative Care (Scotland) Bill and believes that everyone should receive the support they need to have the best possible end of life experience. The National Carer Organisations believe that it is fundamental to establish a legal right to palliative care in Scotland for people of all ages, including children and young people, living with terminal illness and for everyone to have access to palliative care which meets their needs, when and where they need it.

It is also vital that social care responds to the needs of unpaid carers of people living with a terminally illness - ensuring they are being identified, made aware of their rights and being offered the support they entitled to. A right to palliative care should ensure all those affected by terminal illness get the support they need and want, while alleviating the care burden and expectations of unpaid carers. It is vital that people are able to focus the time they have left with the people that matter to them most, not predominantly relying on unpaid care and fighting against systems to try and receive social care support. Scotland must aspire to be a country that encourages open dialogue about the realities of dying, death, unpaid caring and bereavement; empowering people to discuss their care wishes and to have the best possible end of life experience for them.

At present, there is no legal right to palliative care, nor a specific legal requirement in Strategic Plans around palliative care. The levels of which palliative care is included in Strategic Plans is variable across Scotland and is not explicitly stated at all by some Integration Authorities. This has resulted in palliative care mainly being delivered by the charitable sector in a hospice or hospice at home setting, and significant level of care being

[1] Finucane, A.M., Bone, A.E., Evans, C.J. et al. (2019) 'The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision.'

relied on by unpaid carers due to gaps in social care service provision. Going forward, a right to palliative care should be introduced and social care packages need to be robust, flexible and reactive, which meets the often fast changing care needs of people living with a terminal illness, and family members or unpaid carers affected.

The National Carer Organisations agree with Marie Curie that a right to palliative care needs to take an equity informed approach and deliver social care support that is personalised and recognises broader societal barriers, such as the impact of various factors, including poverty and housing, can have. Data also illuminates[2] that there is a significant 24-year gap of healthy life experience between those residing in the most to least deprived areas in Scotland.

A right to palliative care must include proactive and prompt assessment from all relevant professionals who have a role in the care of a person living with a terminal illness. Unpaid carers must also be equal partners in these processes. The National Carer Organisations agree with Marie Curie that assessment should either be standalone or as part of a wider health or social care assessment to establish whether, and to what extent, palliative care is required.

Dovetailing this, local authorities must meet their requirements under the Carers (Scotland) Act 2016 to offer an Adult Carer Support Plan or Young Carer Statement within two working days of being identified by the local authority as caring for someone with a terminal illness, unless there are unforeseen circumstances, in which case they must be offered these as soon as possible. Local authorities must then have a conversation with unpaid carers of people with a terminal illness to identify immediate or urgent personal outcomes and needs of support within five working days of unpaid carers requesting or accepting the offer of an Adult Carer Support Plan or Young Carer Statement. The Adult Carer Support Plan or Young Carers Statement must be prepared within ten working days of unpaid carers accepting the offer and include information on immediate or urgent care, and what support has been arranged.

The National Carer Organisations agree with Marie Curie that a Right to palliative care must ensure access to the specific services required to a person's palliative care needs close to where the person lives and without delay. The National Carer Organisations also agree with Marie Curie that there needs to be minimum service standards for palliative care across Scotland. Including, specific duties on responsible bodies for delivery and implementation, to ensure a person's right to palliative care is fulfilled, protected and respected.

## 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 right to palliative care?

The National Carer Organisations notes that there is no mention of unpaid carers in the WHO definition of palliative care. Unpaid carers provide hands-on care to terminally ill people day to day, often an intensive and extensive role. In doing so, unpaid carers save the health and social care system millions of pounds. Carers must be better supported in this

[2] National Records of Scotland, 2022

role as carer burnout is the most likely factor in a person with a terminal illness being admitted to hospital, hospice or a care home. Therefore, the National Carer Organisations is of the view that carer support must be part 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)?

Strongly agree.

## 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

It is essential that palliative care takes into account the barriers faced by those from BME communities with terminal illnesses as well as their unpaid carers. Work commissioned by Marie Curie identified previously both unmet needs in access to palliative care (including low uptake by BME groups, religious or family issues and structural issues such as hospices being located within predominantly white areas) as well as unmet needs when in receipt of palliative care (such as communication issues and differences in approach to end of life decisions)[3]. In addition, there are different health trends faced by those in BME communities. Different ethnic groups have shown different trends in likelihood of being diagnosed with cancer, and in terms of dementia there has been some evidence to show that some BME groups are more likely to receive early onset dementia[4]

Consideration should also be given to BME unpaid carers for those with terminal illnesses. They also will frequently face barriers, such as less awareness of the financial support that is provided to unpaid carers as well as lower take up of services provided for unpaid carers (often due to cultural/linguistic barriers)[5].

Any work should therefore take into account the barriers discussed above for those in BME communities in ensuring that palliative care is accessible for all. There should be work to understand the barriers and provide solutions.

[3] Natalia Calanzani, Dr Jonathan Koffman, Irene J Higginson (2013), 'Palliative and end of life care for Black, Asian and Minority Ethnic Groups in the UK',
[4] MECOPP (2017), 'The Health of Scotland's Black and Minority Ethnic Communities',
[5] MECOPP (2017), 'Informal Caring within Scotland's Black and Minority Ethnic Communities',

## 4. What is your view on how a right to palliative care should be implemented?

The National Carer Organisations believes that lessons should be learnt from how comparable legislation has been implemented, including the Social Care (Self-directed Support) (Scotland) Act and the Carers (Scotland) Act. While these Acts brought forward welcome new rights for supported people and unpaid carers, they have not been fully or consistently implemented, reflecting many of the wider deficiencies in the social care landscape. The National Carer Organisations, while warmly supporting the right to palliative care, believes that the following set of conditions and processes need to be in place if the right is to become a reality for terminally ill people and their unpaid carers.

**Clear and transparent Information on the Right to Palliative Care**

This is a key first step to enable people to access a right to palliative care. The Carers (Scotland) Act includes a duty in relation to information provision and informing carers of their rights with the Act. Yet despite this, research undertaken by the Coalition of Carers in Scotland in 2023 (5 years after enactment) found that 1 in 3 carers were still not aware of their rights[6]. A duty should be placed on Local Authorities to ensure people with a terminal illness and their carers are aware of the right to palliative care and how to access it.

**A clear pathway to support and timescales**

Accessing social care support can often be a lengthy, bureaucratic and frustrating process, as described in the Review of Adult Social Care in 2022:

> 'For people with care and support needs and their families the challenges of accessing support, only to find they are unavailable or unaffordable, or those seeking support are ineligible, causes unnecessary suffering and hardship.'[7]

In the case of people with a terminal illness it is even more imperative that they have a clear pathway to support, that they receive a prompt response when requiring services and that the system is fully accessible and responsive to their needs. People accessing palliative care should be fast tracked with a duty on local authorities to assess and respond to their needs within a maximum time period. This would reflect the regulations for carers of someone with a terminal illness within the Carers (Scotland) Act, which places a duty on Local Authorities to prepare an Adult Carer Support Plan or Young Carer Statement for carers looking after someone with a terminal illness within 10 working days[8].

**Removal of eligibility criteria**

As part of a pathway to support, the National Carer Organisations believes that the right to palliative care should not be subject to local or national eligibility criteria. This would reflect the government's position in the National Care Service Bill in respect to the right to breaks from caring.

[6] The Coalition of Carers in Scotland (2023), 'Carers Rights in 2023'
[7] Derek Feeley (2022) 'Independent Review of Adult Social Care in Scotland'.
[8] Coalition of Carers in Scotland (2023), 'What to Expect when caring for someone with a terminal illness',

It is our view that once a person meets the definition of being terminally ill and requiring palliative care, the presumption must be that any eligibility threshold has been met. The emphasis should therefore not be on assessing a person's eligibility, but instead on assessing their needs and desired outcomes in relation to end of life care.

Having a clear pathway to support and removing unnecessary processes, would also have the outcome of removing barriers to support for people from poorer socio-economic backgrounds, who are less likely to be able to self-advocate and successfully navigate the current system. The report 'Dying in the Margins' study carried out with the University of Glasgow found that participants understood their care to have suffered because of their socio-economic status.

**Marketplace and choice**

We agree with Marie Curie that there should be a duty on local authorities to ethically commission Minimum Service Standards of palliative care which meets their local population health needs, recognising that this will be different in each area. Services should be designed in partnership with people who are terminally ill and their carers and should have a focus on enabling people to live as full a life as possible.

Deficits in the system will need to be addressed through increased investment, including by expanding existing services to meet demand.

We would also highlight that this is fits well with the National Care Service intention to bring forward a right to a break from caring as the expansion of existing services for palliative care will also bring benefits to unpaid carers in providing opportunities for them to have breaks from caring.

**Carer Support**

The National Carer Organisations is of the view that carer support must be part of the right to palliative care. Unpaid carers still provide the majority of care to people with a terminal illness and where there are deficiencies in the system, these gaps are predominantly filled by unpaid carers.

This is supported by the Marie Curie report comparing the findings of the 1952 "A National Survey Concerning Patients with Cancer Nursed at Home" and a 2022 survey of Marie Curie clinicians caring for people with a terminal illness, which found many overlapping results. Both found that a lack of comprehensive palliative care support at the end of life resulted in patients relying on unpaid carers, many elderly or ill themselves, to deliver palliative care support

As the main care providers, unpaid carers must be involved as equal partners in care planning and have their own support needs identified and met. This is in line with duties within the Carers (Scotland) Act which places a duty on local authorities to involve carers in the care planning for the cared-for person, ensuring that there is a recognition of the care they are willing and able to provide. The need for this carer involvement and access to carer support is even more essential in the care of people with a terminal illness, given the

specialist nature of end of life care, increased need for medical interventions and the additional element for carers of dealing with grief and loss

**Partnership working**
The National Carer Organisations agrees with Marie Curie that Integration Authorities should retain responsibility for delivery of palliative care, but an integrated approach is key, particularly due to health and medical care, being such a significant element of palliative care. The National Care Service may also play a key role, particularly around agreeing service standards, training and a national approach to data collection and monitoring

Both people with a terminal illness, their carers and the third sector must also be valued as equal partners in the delivery of palliative care, with the range and volume of third sector support expanded through ethically commission services.

**Training**
The National Carer Organisations agrees with Marie-Curie that training in palliative care should be a mandatory requirement for all workforces supporting a terminally ill person, including care home staff and social care staff. Marie Curie's findings are that much of the social care workforce does not have end of life care training, despite being expected to deliver care to people with complex needs at home and in care homes.

This should also be extended to unpaid carers, who often have to deliver complex health care, such as the delivery of pain medication, without adequate support or training. Carers centres supporting end-of life carers report that they often talk of their fear of their loved one returning home from hospital, as they do not feel equipped to deal with the full range of their health and care needs. Training would help carers to address their fears and also contribute to people requiring end of life care receiving better care and support. Training should also assist unpaid carers in recognising and being able to articulate their own needs and limitations in delivering palliative care.

**Health Care Records and Future Care Planning**
The National Carer Organisations agrees with Marie-Curie that 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 should include any unpaid carer or carers that are supporting the person with a terminal illness. They should be able to view the plan/record and make notes where appropriate to inform and update the care team on care and any changes in condition.

In addition, every person with a terminal illness should have the opportunity to have a Future Care Plan, which would mirror the right in the Carers (Scotland) Act for carers to have emergency and anticipatory care planning as part of their Adult Carer Support Plan or Young Carer Support

## 5. Are there any other comments you wish to make on the proposed Bill?

For this Bill to be successful it requires a whole systems approach working with all partners in the community with all sectors seen as equals in the strategic planning and commissioning of services, as well as their delivery. The National Carer Organisation would like to see Integration Authorities take a collaborative, whole systems approach, working with unpaid carers, so that they have a say in the delivery of services for the person they are caring for. This will ensure that local palliative care provision maintain a human-rights and person-centred approach.

It also requires review of existing social care models and frameworks which currently are rigidly confined to time and task, meaning that the paid carers are unable to provide the full extent of care patients may require because they only have 15-minute slots per patient. Statutory services delivered in such a limited and rigid basis it puts extra pressure on unpaid carers. There are different ways in which this manifests itself, for example it makes it difficult for unpaid carers to fit in a life outside of caring, including going to work. The right to palliative care is an opportunity to ensure this time constrained approach is replaced with one which has person-centred outcomes at the heart of its delivery.

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