



Marie Curie response

Consultation on Bill of Rights for Northern Ireland

Care and support
through terminal illness

ABOUT MARIE CURIE

1. Marie Curie is a leader in the provision of care and support to people affected by terminal illnesses in Northern Ireland. We provide a range of services including the Marie Curie hospice in Belfast, Nursing Service and Helper Service. Each year we provided care and support for over 4,000 people living with a terminal illness, their carers and loved ones.
2. We welcome the opportunity to respond to this consultation on a Bill of Rights for Northern Ireland. The consultation questions cover a wide range of important themes, but we have only commented on those we feel are relevant to our work and the patients and carers we support.

THE RIGHT TO HEALTH OF UNPAID CARERS

3. Providing unpaid care to a loved one, especially when the person is terminally ill and may be approaching the end of their life, is a round-the-clock and exhausting role. The impact on carer's physical health and mental wellbeing is well documented, with many carers experiencing burnout and significantly poorer health outcomes than their non-carer peers. In this context, robust measures to protect carer's right to health are critical.
4. In 2014, the NI Human Rights Commission published an analysis of the human rights of carers in Northern Ireland, reporting that local carers "often encounter difficulties in obtaining a [Carers] [A]ssessment and that the outcomes often **fail to address the conditions necessary in order to fulfil the right to health** [emphasis added]." ^[1] Evidence strongly suggests that these issues still exist in 2021 and we would support protections to address them in the proposed NI Bill of Rights.
5. The Carers and Direct Payments Act NI places a statutory duty on HSC Trusts to inform carers about their right to have an assessment. However, Carers NI's 2019 State of Caring report showed that only 26% of local carers had had an assessment, or a review of their assessment, in the previous 12 months. ^[2] There is long-standing evidence that awareness of, and access to, Carers Assessments may be a particular problem among older carers ^[3] – with just 2% of older carers in 2018 reporting that their GP had given them information about how to get regular breaks from caring. ^[4] Marie Curie's own research has demonstrated that robust support and respite is critical to helping older carers of terminally ill people maintain their own health and wellbeing. ^[5]
6. Even if a carer is able to access a Carers Assessment, significant numbers report that these assessments do not properly consider their need for support to look after their own physical and mental health or have regular breaks. ^[2] And, finally, in the event that an assessment does adequately identify a carer's need for support, there is no statutory obligation on their HSC Trust to provide this support – unlike other jurisdictions like England and Scotland.
7. In 2017, the Power to People report recommended that the rights of carers in Northern Ireland are put on a legal footing, ^[6] and we believe the proposed Bill of Rights provides one suitable mechanism

¹ Northern Ireland Human Rights Commission (2014). The human rights of carers in Northern Ireland.

² Carers NI (2019). State of caring: A snapshot of unpaid care in Northern Ireland.

³ Commissioner for Older People for Northern Ireland (2014). Supporting older carers: Examining the reasons for the low uptake of Carers Assessments by older carers in Northern Ireland.

⁴ Carers Week (2018). Supporting carers to be healthy and connected: Research summary.

⁵ Marie Curie (2018). Lost retirement: The impact on older people of caring for someone with a terminal illness.

⁶ Expert Advisory Panel on Adult Care and Support (2017). Power to people: Proposals to reboot adult care and support in NI.

to deliver and/or support this, particularly in regard to a carer's right to health. As a minimum, this should enshrine the rights of all carers in Northern Ireland to:

- be properly informed about the right to an assessment of their needs; and
- access the support that they need to maintain their own health and wellbeing, including respite care.

THE RIGHT TO SOCIAL SECURITY FOR PEOPLE WHO ARE TERMINALLY ILL

8. Marie Curie strongly supports the inclusion of additional protections around the right to social security in a Bill of Rights for Northern Ireland. The office of the UN High Commissioner for Human Rights describes a number of key elements of the right to social security,^[7] including:
 - Availability – A social security system needs to be in place under domestic law to ensure that benefits are effectively administered and supervised.
 - Accessibility – A social security system should cover all persons, especially those belonging to the most disadvantaged and marginalised groups, without discrimination.
9. We believe that elements of the existing social security system in Northern Ireland – specifically, the discriminatory outcomes arising from the Special Rules for Terminal Illness (SRTI) in benefits law – fail to meet these criteria.
10. SRTI allow some dying people to get fast-track access to welfare payments without filling in extensive paperwork, waiting through qualifying periods or enduring disability assessments. When the system works, it allows dying people to access the financial support they need, when they need it – supporting them to enjoy the best quality of life possible.
11. Many dying people are unfairly excluded from this fast-track system, however, because eligibility is tied to a life expectancy of six months or less. This arbitrary timeframe fails to recognise the unpredictable trajectories of many terminal conditions – particularly non-malignant diseases – which makes it incredibly difficult for medical professionals to accurately gauge how long patients may have left to live.
12. It is important to note that the different treatment of terminally ill people who cannot meet the six month life expectancy criterion has already been ruled as in breach of Article 14 (protection from discrimination) of the European Convention on Human Rights in a case before Belfast High Court in June 2020.^[8] The judgement of this case stated that “this difference in treatment is manifestly without reasonable justification”, and the terminally ill plaintiff was awarded a financial sum for the “upset, distress, annoyance, inconvenience, worry and humiliation” caused.^[9]
13. Marie Curie would warmly support inclusion in the proposed Bill of Rights of a right for all terminally people in Northern Ireland to access the social security support they need, without bias or discriminatory outcomes based on arbitrary estimations of their life expectancy.

For more information please contact:

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⁷ United Nations Human Rights Office of the High Commissioner. OHCHR and the right to social security. Available at: <https://www.ohchr.org/EN/Issues/RightSocialSecurity/Pages/SocialSecurity.aspx>.

⁸ See: <https://lawcentreni.s3.amazonaws.com/McA11286Final-Typed.pdf>.

⁹ Law Centre NI. Terminally ill woman receives award for ‘distress and humiliation’ caused by terminal illness rules.