



## 12 recommendations to support carers involved in the delivery of Palliative Care Provision in Northern Ireland

Northern Ireland has 222,000 unpaid carers, 59% of whom are women, providing care and support for family members, friends or neighbours who have a long-term illness, disability, or who are getting older. We expect the number of carers to rise in line with ageing predictions and research from the 4 Chief Medical Officers that the UK population is getting older and will experience more sickness with age<sup>1</sup>. Research shows NI has the highest proportion of carers in the UK. It has also been estimated that the 2021 census figure does not reflect an additional 98,000 people in NI who started caring during the pandemic<sup>2</sup>. An estimated 90% of those who could benefit from palliative care do not receive it. This unmet need results in lower quality of life for patients and increased avoidable hospital and emergency department admissions<sup>3</sup>.

1. Carers should be centrally involved in any palliative framework designed for Northern Ireland. They are a critical part of the death and dying process. The projected increase in the population aged 65+ in Northern Ireland is set to grow by 50% by 2047 and therefore we have a significant need to put policies in place now.
2. Carers NI believes any new palliative care strategy should specifically recognise the unique challenges faced by unpaid carers providing care and support for someone with a terminal illness, approaching the end of life, at the time of death, and following it through bereavement and grief. This strategy should identify specific support for carers such as access to training, respite care, financial support, mental health support and bereavement services.
3. Carers need support in order to provide the best care for their loved one who is dying. This need is explicitly referenced in the DOH 2022-2032 Cancer Strategy<sup>4</sup>. But currently carers are not coping well. Carers NI 2024 State of Caring (SOC) survey told us:
  - **81%** of carers strongly agree or agree that being a carer has negatively affected their mental health
  - **A third (34%)** described their mental health as either bad or very bad.
  - **1 in 4 (25%)** said their physical health was bad or very bad and
  - **57%** said they felt overwhelmed by their caring role often or always.

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<sup>1</sup> Rising to the challenge of multimorbidity Whitty et al 2020 <https://www.bmj.com/content/368/bmj.l6964>

<sup>2</sup> This research is based on polling carried out by YouGov plc in May 2020 for Carers UK

<sup>3</sup> RAISE 2025 research paper for HC Introduction to palliative and end of life care in Northern Ireland.

<sup>4</sup> NI Cancer Strategy p85 states: "In addition, people providing unpaid care for loved ones with non-curative cancer and at end of life should have access to support services to meet their own health and wellbeing needs. This includes regular breaks from caring and reliable respite care." The NI Cancer Strategy section on carers states: "Support and care provided by families and informal carers is vital to the wellbeing of patients given their assistance in managing medications, treatment regimes, symptom management, personal care, social and psychological support. Providing informal care is challenging for many and can have a negative impact on both physical and mental health." <https://www.health-ni.gov.uk/publications/cancer-strategy-northern-ireland-2022-2032>

4. Poverty & End of Life Care: Marie Curie research<sup>5</sup> has found one in every five people who died in Northern Ireland in 2023 were in poverty. Carers here already experience more poverty than those with non caring responsibilities<sup>6</sup>. If they receive Carers Allowance (CA) our own research shows this rises dramatically to 48%<sup>7</sup>. CA stops 8 weeks after a person dies which would add to any financial strain for a carer coping with the death of their loved one. At Carers NI and across the UK we are campaigning for this benefit to be extended to 6 months.
5. Access to paid carers leave and stronger bereavement policies would help carers immensely. Taking time off to look after a person who is dying needs careful and considered support from employers. Creating a growing awareness amongst employers of death and dying and impacts on carers is an important step for the whole NI Executive and specifically the Department for Economy.
6. Out of hours Care: We need to standardise the availability of palliative care core services across populations and regions in NI including availability of approved practitioners to administer medicines in the overnight period and professionals to help with personal tasks. Too often carers are filling in the gaps at extreme cost.
7. A campaign to raise awareness about palliative and end of life care is required. [UU 2023 research](#) found misconceptions still existed with many respondents assuming palliative care was only for older people, those in the final six months of life and only available in a hospital setting.
8. Gendered impacts of caring across the ages: In Northern Ireland nearly 60% of unpaid carers are women. The ages of those who are being cared for is across the life span too with 41% caring for a parent, 39% caring for a son or daughter and 25% for a spouse or partner (SOC results).
9. Carer support services in the third sector supporting unpaid carers should be included as key partners and supported and provided with additional funding through the commissioning process to provide dedicated support.<sup>8</sup>
10. Carers Health: We need to improve access to national screening programmes and health checks for unpaid carers. There is convincing evidence that caring impacts upon physical health and should be considered as a social determinant of health. The NI State of Caring 2023 survey found that more than 1 in 3 carers have put off health treatment for themselves because of the demands of caring. Being a carer can involve months or years of life. Our research has shown 21%

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<sup>5</sup> Dying in the Margins: The Cost of Dying 2023 Marie Curie <https://www.mariecurie.org.uk/document/dying-in-the-margins-2023>

<sup>6</sup> Carer Poverty Commission <https://www.carersuk.org/ni/news-and-campaigns/carers-poverty-commission/>

<sup>7</sup> Carers NI State of Caring report on Finances and Employment Jan 2025 <https://www.carersuk.org/media/fr5fixqo/state-of-caring-ni-2024-finances-employment.pdf>

<sup>8</sup> Evidence has shown a need to deliver improved services for informal carers of patients with cancer in Northern Ireland. See: Santin, O., Murray, L., Prue, G., Gavin, A., Gormley, G., Donnelly, M. (2015) 'Self-reported psychosocial needs and health-related quality of life of colorectal cancer survivors', European Journal of Oncology Nursing, 24: 121-129. <https://pubmed.ncbi.nlm.nih.gov/25800658/>; Santin, O., Mills, M., Treanor, C., Donnelly, M. (2012) 'A comparative analysis of the health and wellbeing of cancer survivors to the general population', Journal of Supportive Cancer Care, 20,10: 2545-2552. <https://pubmed.ncbi.nlm.nih.gov/22262132/>; Treanor, C., Santin, O., Mills, M., Donnelly, M. (2012) 'Cancer survivors with self-reported late effects: Their health status, care needs and service utilisation', Psycho-oncology, 22: 2428-35. <https://pubmed.ncbi.nlm.nih.gov/23677669/>; Santin, O., Treanor, C., Mills, M., Donnelly, M. (2014) 'The health status and health service needs of primary caregivers of cancer survivors: A mixed methods approach', European Journal Cancer, Volume 23, Issue 3: 333-339. <https://pubmed.ncbi.nlm.nih.gov/24313908/>

of carers have been caring more than **20 years** and 44% of respondents said they provide more than 90 hours of care per week.

11. Bereavement & post bereavement: support for carers post-bereavement should be part of this review and addressed in any connected public policy. Many carers will get no support from the state following the death of the person they are caring for, whether that is financial, emotional, bereavement, or rebuilding lives, e.g. return to work and employment. This is often a bit of black hole in carer policy, and we feel it should be identified and recommended for further action.
12. Investment from NI Executive in death and dying: Good to see a reference to this in new 2024-2027 Programme for Government however there is no point in well designed and informed plans lying on shelf ie DOH 2022 Advanced Care Planning strategy which unfortunately has not been implemented.