



National Carer  
Organisations

**National Carer Organisations response to Palliative Care Matters for All: Strategy consultation**

The National Carer Organisations (NCO) welcome the opportunity to submit a response to the Palliative Care Matters for All: Strategy consultation.

The NCO 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 NCO 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.

This response follows previous work by the NCO responding to the proposed Right to Palliative Care Bill submitted by Miles Briggs MSP.

## Section A: Overall Strategy

### Question 1a. Do you agree with the aims for this strategy?

**Agree**

### Question 1b: Please add any comments you have about the strategy aims here:

The Strategy must have a specific aim that recognises and addresses the unique challenges faced by unpaid carers providing care during a terminal illness, through end of life, and at bereavement as well as beyond. This should include specific recommendations and actions points that relate to access to training, information and support, respite care, financial support and mental and physical health support. These measures would help unpaid carers provide better care while maintaining their own wellbeing.

It is critical that the Strategy also includes a commitment from Government to hold a nationwide conversation around dying, death and bereavement to encourage a more open and honest approach to dealing with these issues and tackling the taboo that they have become. Such a national conversation must engage more widely than within families and communities but extend to include all aspects of society. For unpaid carers this must explicitly include employers. Juggling paid employment and caring responsibilities is already challenging and extremely stressful, with many carers unable to sustain their careers, but this can be even more intense when facing end of life care (whether the carer is providing this care at home, or it is being provided elsewhere, for example, at a care home or a hospice). Developing a nation of supportive employers and employment practices, and the promotion of employers' role of being part of the community that supports people who are terminally ill and approaching the end of life could prevent carers losing employment and the financial insecurity that follows.

Having proactive supportive policies and practices - alongside mandatory unpaid carer awareness training - in education institutions could prevent unpaid carers dropping out of education. Carers Trust research found that unpaid carers are four times more likely to drop out of college or university than those that are not unpaid carers, which then impacts their life choices and future aspirations.

### Question 2a. Do you agree with the strategy cornerstones, which form the basis for the strategy and delivery plans?

**Agree**

### Question 2b: Please add any comments you have about the four strategy cornerstones here:

Regarding the 'cornerstone': "Ensuring equity and equality of access to palliative care for anyone who needs it," for unpaid carers and cared-for people with protected characteristics there is a substantial amount of work that currently needs to be carried out to ensure this cornerstone can be achieved. For example, unpaid carers from Scotland's BME communities have reported significant issues in terms of accessing services, including linguistic barriers and a lack of culturally appropriate services (such as dietary, religious or gender requirements). (Source: [mecopp\\_briefing\\_sheet\\_03.pdf](#)) It is therefore important when undertaking work to ensure equalities in palliative care services that the needs of unpaid carers and cared-for people within BME communities are therefore considered.

There is a need to ensure that all unpaid carers with protected characteristics have equity of access, including to information. For example, Marie Curie ([Source: Hiding Who I am: the reality of end of life care for LGBT people](#)) notes the lack of recognition of the variety of support systems and complexities, fear of discrimination and assumptions around identity and family structure experienced by LGBT people.

It is also important to consider rural and island carers in this context who have additional barriers, including, acute services located off-island, less access to community health services, issue of transport and geography, particularly in the Winter months and less access to breaks from caring for unpaid carers.

Throughout the Strategy consideration must be given to ensuring that all actions are 'equality-proofed' to include the needs of carers with protected characteristics, addressing barriers and identifying gaps. It is important that no one is left behind.

## **Section B: Strategy outcomes**

### **Question 3a. Do you agree with strategy outcome 1 and the proposed actions being developed to deliver this outcome?**

**Agree**

#### **Question 3b: Please add any comments you have about outcome 1 and its actions here:**

Identifying carers is critical. Carers Scotland research (State of Caring 2024) found that a quarter of carers took more than 5 years to identify themselves as a carer, missing out on practical and financial support for their caring role. The same research found that only 20% of carers have had an assessment of their needs in the last year. It is therefore important that NHS and local authorities fulfil their duties under the Carers Act (2016) to identify carers as early as possible and deliver Adult Carer Support Plans to ensure that they receive the support they are entitled to. This should include ensuring that carers are connected to support in their own communities including carers centres. This clear approach can help to reduce carer poverty, ill health and prevent the breakdown of care arrangements.

The commitment to providing "resources for people from diverse groups and communities" is important and for unpaid carers from BME communities, there must be consideration of how these resources will be delivered. Consideration should for instance be in providing resources in community languages and making use of audio-visual resources for those with limited literacy. A wide variety of communication methods will therefore help ensure that as many of the 308,337 people reported in the 2022 Scotland's Census as having some form of lower skill in either reading, writing, or speaking English can access the necessary information.

Resources should also be available in non-digital formats as some BME communities are more likely to be digitally excluded, such as many members of the Gypsy/Traveller community. (Source: [MECOPP Briefing Sheet 15.pdf](#))

We believe there should be a specific outcome regarding engagement with employers and unions to create a supportive working environment for unpaid carers to provide or support palliative care for the person they are caring for while continuing to be in employment. This should include ensuring carers know about their employment rights and to encourage employers to develop and promote bespoke solutions to support their employees who are affected by a terminal diagnosis, managing end of life care, and bereavement.

### **Question 4a. Do you agree with strategy outcome 2 and the proposed actions being developed to deliver this outcome?**

**Agree**

#### **Question 4b: Please add any comments you have about outcome 2 and its actions here:**

Unpaid carers should be considered equal partners in care. Therefore, there should be a specific outcome setting out the role of carers as equal partners in care and stating their involvement in the development of palliative care services. This also reflects the duty on the Carers Act.

Unpaid carers play a key role in palliative care delivery and should be explicitly included in governance frameworks and innovation initiatives. Their insights can inform practical improvements in care delivery.

HSCP carer strategies should be updated to include specific activities to support carers providing support to those living with a terminal illness, approaching the end of life and at the point of death linking to their local palliative care strategies.

Carers Centres and other services in the third sector supporting unpaid carers should be included as key partners and provided with additional funding through the commissioning process to provide dedicated support.

**Question 5a. Do you agree with strategy outcome 3 and the proposed actions being developed to deliver this outcome?**

**Agree**

**Question 5b: Please add any comments you have about outcome 3 and its actions here:**

We support the mention of carers in the outcome noted above but worry about the lack of reference to carers in the actions. Any data collection activity around palliative care must include unpaid carers. Data must identify the number of unpaid carers supporting people, the level of intensity of that caring role, its complexity, as well as the impact it has on the quality of their life, as well as their physical and mental wellbeing. Data should also be collected around bereavement and grief, where possible. Collecting this data around unpaid care will be significant in informing future service design and provision of palliative and other services to support terminally ill people. With an increasing amount of care for terminally ill people, including at the end of life, being provided by unpaid carers in the community, this data is essential in order to ensure that those being cared for and their carers to receive person centred care that meets their needs and delivers positive outcomes.

Ensuring that there is sufficient data available to measure poverty and the impact of social security benefits delivered through Social Security Scotland, the Department of Work Pension and local authorities is essential to ensure that the growing issue of poverty at end of life can be examined and improvements made to the financial support offered to those households where someone is living with a terminal illness.

**Question 6a. Do you agree with strategy outcome 4 and the proposed actions being developed to deliver this outcome?**

**Agree**

**Question 6b: Please add any comments you have about outcome 4 and its actions here:**

The final action listed above will be extremely important for BME unpaid carers and those they care for. As already noted, there are a number of barriers to accessing support services including communication and cultural barriers. Some communities are already less likely to access services due to substantially lower life expectancy, such as the Gypsy/Traveller community (Source: [MECOPP Briefing Sheet 15.pdf](#)).

There will need to be substantial research undertaken to understand the specific issues affecting specific communities to ensure that the work is tailored in the correct manner.

An outcome should be included to increase and improve access to national screening programmes and health checks for unpaid carers. There is strong evidence that caring impacts upon physical health and in State of Caring 2023, 41% of carers said they had put off health treatment because of their caring role. Earlier diagnosis of significant illness is vital, as is the ability to be provided with the right support to enable carers to attend appointments and treatment. Specific attention should also be paid to those carers with protected characteristics and working to ensure equity of access.

Outcomes should also be included to identify carers, provide Adult Carer Support Plans and deliver support for caring. This should also include clear outcomes and actions for supporting unpaid carers in the hospital discharge process. Research by Carers Scotland (State of Caring, 2023) found that 60% of carers were not informed or involved about hospital discharge despite being expected to

provide care. The Carers Act (2016) sets out carers rights around this and the NHS must do more to uphold these commitments.

**Question 7a. Do you agree with strategy outcome 5 and the proposed actions being developed to deliver this outcome?**

**Agree**

**Question 7b: Please add any comments you have about outcome 5 and its actions here:**

We are supportive of future planning for care and a Once for Scotland approach but it is vital to ensure that this fully involves people with lived experience in developing solutions. In addition, a wide variety of voices from minority groups must be considered. This means working with multiple ethnicities and multiple people from each ethnicity to get robust data. Voices should also include those such as unpaid carers from BME communities. There may be some wish to consider working with third sector organisations that work with certain communities who may have greater trust than public authorities when undertaking this work.

In addition, greater information, better communication, and earlier conversations are needed around DNACPR, including developing publicly available resources to support informed decisions around future care planning. During the pandemic, people with learning disabilities and older people experienced these being placed on their files without their knowledge or consent, or that of their unpaid carer. This was a deeply distressing experience and eroded trust in those providing care. ([reference COVID inquiry](#)).

Carers should be given an equal role in care planning. We know from Carers Scotland research (State of Caring, 2023) that carers are not adequately involved in care planning, if at all. Not only should carers be involved, but they should be able to amend (where appropriate) care plans to support the better delivery of care. In addition to this, carers needs should be identified through this process and recorded as part of care planning, so that appropriate support can be identified, including referral for an Adult Carer Support Plan.

**Question 8a. Do you agree with strategy outcome 6 and the proposed actions being developed to deliver this outcome?**

**Agree**

**Question 8b: Please add any comments you have about outcome 6 and its actions here:**

The development of an update of the public information leaflet is welcomed and it should be developed in collaboration with people with lived experience. In line with our earlier points, this must include ensuring that public information is suitable for all members of our communities. For example, with specific and culturally appropriate information available for minority ethnic people, easy read versions, and information available in a variety of formats (audio, written, video).

In addition to this, bespoke information resources for children and young people affected by bereavement would also be welcomed, designed, and developed with and for young carers.

**Question 9a. Do you agree with strategy outcome 7 and the proposed actions being developed to deliver this outcome?**

**Agree**

**Question 9b: Please add any comments you have about outcome 7 and its actions here:**

Transitions are a challenging time for all parent carers but particularly so for those with a young person with a life limiting condition. Actions must include considering availability of dedicated resources, including hospice and short break provision, for 'older young people' and their families to give confidence that support for quality complex and palliative care will be a priority. This should

include working with Social Security Scotland and the DWP on the impact of financial changes when their child reaches the end of their education – a time where family resources can shrink significantly.

**Question 10a. Do you agree with strategy outcome 8 and the proposed actions being developed to deliver this outcome?**

**Agree**

**Question 10b: Please add any comments you have about outcome 8 and its actions here:**

Unpaid carers, particularly, those who provide support to someone at home or in a community setting will often be delivering complicated care, including medical interventions, as well as physical care including lifting and bathing. This can be physically demanding, but also stressful for unpaid carers. Unpaid carers must have access to the same information and training opportunities as paid staff.

This Strategy therefore must include clear actions on how to provide a range of information, support, and training to all unpaid carers supporting someone with a terminal illness and approaching the end of life. Consideration should be given to how this can be delivered in a way that fits around their caring role. Resources could include short online courses, literature, and direct support and training from health and social care professionals.

Supporting unpaid carers through appropriate education support will not only increase the chances of the carer being better able to provide care to the person they are caring for, but also reduce anxieties and emotional distress. In turn, this would increase unpaid carers confidence around the care they deliver, especially in more complex care, involving medication and other healthcare tasks.

**Question 11. Please add any further comments you have about the draft strategy outcomes and actions here.**

**NA**

**Question 12a. Community action and support - Do you think this strategy explains why it is important to encourage people, families and communities to come together, support each other, take action and talk more openly?**

**Yes**

**Question 12b: Please add any comments you have about how to do this better in Scotland.**

As noted earlier, we agree there is a need for greater discussion on both future care planning and death and dying. We believe that this conversation must extend beyond community and family conversations into our whole system to ensure that these discussions inform the development of outcomes that are not just for health and social care systems but also for wider local authority services, housing, community planning, employability, employment and economies.

**Question 13a. Earlier access to palliative care - Do you think this strategy explains why getting palliative care long before someone is dying can help adults, children, their families and carers?**

**Yes**

**Question 13b: Please add any comments you have about earlier access to palliative care here.**

The Strategy itself is seeking to extend this understanding, but the question will be in its implementation across Scotland and in building this understanding not just with people with serious health conditions and their families/ unpaid carers but with service providers, decision makers and planners. Ongoing opportunities should be taken to learn from other countries experiences and from emerging research.

**Question 14a. Improving access to palliative care and support - Do you think that the actions in this strategy can improve the experiences of people with different personal characteristics and circumstances?**

**Yes**

**Question 14b: Please add any comments you have about impacts of the strategy on these or other groups of people here.**

In terms of race and ethnic group, the Strategy does make some positive comments regarding working with members of minority communities, tackling barriers and improving some of the communication issues that exist. These are all issues that have been identified as barriers for BME unpaid carers and those they care for. However, there is a lack of more detailed information in the Strategy about how this will be practically achieved, and we would urge the formation of a concrete plan to help remove the barriers that do exist.

**Question 15a. Language and terms used in the strategy - Do you think the strategy explains what is meant by the terms palliative care for adults; palliative care for children; care around dying; and future care planning?**

**Yes**

**Question 15b: Please add any further comments you have about any of the terms that are used in the draft strategy.**

It can be difficult to see where palliative care ends and care around dying begins. They are closely intertwined but it should bring in the terminology around holistic support (as the palliative care definition) rather than the definition 'whole person care' which may be less clear.

**Question 16. Please add any other comments or suggestions you have about the draft Palliative Care Strategy here:**

NA