

## Scottish Government Consultation on Draft Carers Strategic Policy Statement, December 2019

### About Hospice UK

Hospice UK is the national charity for hospice and palliative care, supporting over 200 hospices across the UK. We work to ensure all adults and children living with a terminal or life-shortening illness receive the care and support they need, when they need it. Our mission is to transform the way society cares for the dying and those around them.

Hospice UK supports the breadth, dynamism and flexibility of modern hospice care by influencing national and local policy, improving quality of care through the sharing of good practice, and providing resources, education and training, and grant programmes. In Scotland, hospice care providers support over 20,000 people every year, through inpatient, outpatient, day hospice and hospice at home services, and bereavement support.

### Question 1

**The Carers Strategic Policy Statement aims to map the main policies across the Scottish Government which are relevant to carers; and set out the overall approach and outcomes these policies contribute towards. Do you agree that the draft achieves this?**

The draft Carers Strategic Policy Statement pulls together a wide range of policies that are relevant to carers. However it is missing two key areas:

- policies relating to carers who are caring for people who are terminally ill, and
- policies that support carers once their caring role comes to an end, including around bereavement support and support around funeral expenses

In addition, it needs to include an overarching strategic aim that the long-term financial negative impacts of caring should be minimised, including support for carers to return to work.

Carers play a vital role in supporting people with palliative care needs. It is important that they are identified as carers as early as possible in the cared-for person's disease trajectory, so that their needs can be assessed and met, and so that they can effectively carry out their caring role. The level of care that a carer provides to someone with a terminal illness can escalate rapidly in a short space of time, and can be very high. A lack of support can put both the carer and the cared-for person at risk of reaching crisis point, resulting in a breakdown in care. Research by Marie Curie identified missed opportunities to identify people in a caring role and highlighted the importance of respite, physical support, psychological support, communication and co-ordination for carers supporting people at the end of life<sup>1</sup>.

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<sup>1</sup> <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/marie-curie-and-macmillan-getting-it-right-for-carers-final-report-november-2018.pdf>

Despite the importance of identifying and supporting carers of people who are terminally ill, the draft Carers Strategic Policy Statement only mentions palliative and end of life care in passing, in relation to the dementia strategy. It does not refer to existing policies relating to carers and palliative and end of life care.

The policy statement needs to highlight the unique role of carers who are caring for people who are terminally ill, their specific needs and the policies that are in place to support them. The Carers (Scotland) Act 2016 requires Scottish Ministers to set timescales for preparing Adult Carers Support Plans and Young Carer Statements for carers of terminally ill people, in their last six months of life. These regulations will be laid in due course and should be referred to in the Carers Strategic Policy Statement.

The Scottish Government's Strategic Framework for Action on Palliative and End of Life Care<sup>2</sup> is clear that its key approach "*is to help ensure that the wellbeing of people, families and **carers** is supported, even as health declines*" and that "*the needs of the thousands of unpaid carers, their families and others within communities who support people at the end of their lives*" must be considered.

The Strategic Framework for Action emphasises the need to involve carers in timely and focused conversations with professionals to plan care and support towards the end of life. It makes specific commitments around improving identification of people with palliative care needs, the importance of anticipatory care planning, and recording and sharing this information electronically. Advanced care plans, palliative care registers and Key Information Summaries are important ways that carers can be identified and supported, and this should be reflected in the Carers Strategic Policy Statement.

The Strategic Framework for Action also includes a wider commitment around supporting greater public discussion around death, dying, bereavement and care at the end of life. This links to important work, led by the Good Life Good Death Good Grief initiative, to support compassionate communities, where local communities are taking community action to improve people's experiences of death, dying, loss and care.

It is vital that support for carers extends into the bereavement period. The draft Carers Strategic Policy Statement does not make reference to policies that support carers following the death of the person they have been caring. This includes bereavement support and support around funeral expenses.

Carers are not currently getting the bereavement support they need. Research commissioned by Hospice UK and Sue Ryder in 2018 found that a quarter of bereaved people in Scotland who reported that they would have wanted bereavement support were unable to access it<sup>3</sup>. The Carers (Scotland) Act 2016 requires local authorities to provide information and advice to carers around bereavement support services. If a carer anticipates a need for bereavement support, in advance of the death of a cared-for person, this should be considered as part of the Adult Carers Support Plan/Young Carer Statements. Local Authorities should also provide specific information to carers who are eligible for Bereavement Support Payment.

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<sup>2</sup> <https://www.gov.scot/publications/strategic-framework-action-palliative-end-life-care/>

<sup>3</sup> Sue Ryder and Hospice UK (2018) Bereavement support in Scotland:

<https://www.sueryder.org/sites/default/files/2018-10/Bereavement-Support-in-Scotland-report-Sue-Ryder-Hospice-UK-2018.pdf>

Funeral poverty has become an increasing concern for bereaved families and carers in Scotland. The Carers Strategic Policy Statement needs to refer to the Scottish Government's recent guidance on funeral costs, which states that local authorities should put in place measures to support and assist people who are unable to meet the costs of arranging a funeral. It also needs to refer to Funeral Expense Assistance and the requirement for Local Authorities to provide information to carers on this.

The Carers Strategic Policy Statement includes as a strategic outcome that carers are able to *"take up or maintain meaningful employment alongside caring"*. However it can be difficult for carers to juggle working and caring responsibilities and carers may have to stop working because of this. This can be especially true of carers supporting someone at the end of life, when the level of care they provide can be very high. The Policy Statement needs to include a strategic aim that the long-term financial negative impacts of caring should be minimised, including support for carers to return to work.

## **Chapter 1 – Introduction**

### **Question 3**

**Do you agree with the vision and principles as proposed in the strategic framework?**

**Please provide reasons for your response.**

The vision and principles should also include that carers will be supported after their caring role has come to an end. This should encompass support in the bereavement period, if the person they are caring for dies. It should also include support to return to work, if a carer had to give up work during the caring period.

The importance of early identification of people in a caring role should also be highlighted as an overarching principle.

## **Chapter 2 - Carer Voice and Engagement**

### **Question 4**

**Do you agree with the proposed strategic outcome:**

**"Carers voices are heard and their views and experiences are taken into account in decisions which affect them?"**

**Please provide reasons for your response.**

The strategic outcome could be amended to read *"Carers voices are heard and their views and experiences are taken into account in decisions which affect them **and the person they are caring for**"*

## **Chapter 3- Health and Social care support**

### **Question 6**

**The proposed strategic outcome is one of the "National Health and Wellbeing Outcomes" set in legislation to guide the integration of health and social care:**

**“People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing?”**

**Do you agree with our proposed approach of using the same outcome for this document?**

Agree

## **Chapter 4- Social and financial inclusion**

### **Question 8**

**Do you agree with the proposed strategic outcomes:**

**“Carers access the financial support and assistance they are entitled to?”**

**“Carers are able to take up or maintain meaningful employment alongside caring?”**

**“Carers can participate in and are valued by their community and wider society?”**

**Please provide reasons for your response.**

There should be a strategic outcome that the long-term financial negative impacts of caring should be minimised, including support for carers to return to work.

It is not always possible for carers to *“take up or maintain meaningful employment alongside caring”*. It can be difficult for carers to juggle working and caring responsibilities and carers often have to stop working because of their caring responsibilities. This can be especially true of carers supporting someone at the end of life, when the level of care they provide can be very high. In these cases there should be support for a carer to return to work when they are able to. While there is reference within the body of the document to supporting carers to re-enter employment, this is not reflected in the overarching strategic outcomes.

Hospice UK believes that the long-term negative financial and labour market effects that carers can experience as a result of their caring need to be mitigated. At a UK level we have called for a statutory entitlement for carers to return to work following a fixed absence period of up to two years to care for a loved one. While this relates to the UK Government, it is important that Scottish policy also reflects the need for carers who have had to stop working to be supported to return to work when they are able to. Scottish Government may be interested to know that Hospice UK recently launched a Compassionate Employer scheme to help employers improve support for staff living with or caring for someone with a terminal illness, or experiencing bereavement<sup>4</sup>.

The final strategic outcome *“Carers can participate in and are valued by their community and wider society?”* should be amended to read **“are supported and valued by their community and wider society”**. This would then incorporate the growing and important work around compassionate communities and services such as befriending. These initiatives, for example Compassionate Inverclyde<sup>5</sup>, are being delivered by hospices, other third sector organisations

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<sup>4</sup> <https://www.hospiceuk.org/what-we-offer/compassionate-employers>

<sup>5</sup> <https://ardgowanhospice.org.uk/how-we-can-help/compassionate-inverclyde/>

and community groups and there is wider work to support compassionate communities being led by the Scottish Partnership for Palliative Care.

## Contact

Helen Malo, Policy & Advocacy Manager Scotland  
Email: [h.malo@hospiceuk.org](mailto:h.malo@hospiceuk.org) Tel: 07852 244 304