



# Manifesto priorities

for Scottish Parliament  
Elections 2021

The COVID-19 pandemic has brought into sharp focus the importance of end of life care and the support needed for families and carers throughout this time and into bereavement. Palliative care is about supporting people to live as fully and as well as they can to the end of their lives, however long that may be and in whatever setting they are living. But in Scotland, too many people – one in four – are missing out on the care they need at the end of life.

Ahead of the Scottish Parliament elections in May 2021, Hospice UK is calling on all political parties to commit to key priorities in their manifestos to support people in Scotland living with a terminal or life-shortening condition, and to support their families and carers..

## The next Scottish Government should:



- 1** Commit to a new national plan for palliative and end of life care for Scotland that puts **tackling inequalities** at its heart
- 2** Plan for, invest in and develop the infrastructure for **bereavement support** for everyone who needs it, including building capacity and resilience within local communities



- 3** Deliver a **proactive, responsive and flexible social care** system that meets the changing needs of people living with a terminal illness
- 4** Increase support for unpaid (family) **carers**, including bereaved carers



- 5** Commit to working with Scottish hospices to secure a long-term, sustainable and transparent **funding solution** for the charitable hospice sector

# Background

In 2019, 58,100 people died in Scotland<sup>1</sup>. It is estimated that about 44,000 of these people had palliative care needs<sup>2</sup>. However, one in four, 11,000 people across Scotland, missed out on the care they needed at the end of life<sup>3</sup>.

The need for palliative care is increasing in Scotland as more people are living longer with multiple conditions, and the care they need is becoming more complex. It is estimated there will be nearly 16% more deaths in Scotland in 2040, compared to 2016, with 45% of people dying aged over 85<sup>4</sup>. The number of babies, children and young people living with a life-shortening condition in Scotland has been rising year on year and is currently estimated at 16,700<sup>5</sup>.

We're also seeing a change in where people are dying, with more people dying in their own homes or in a care home, compared to in hospital. The COVID-19 pandemic has rapidly accelerated this shift, with the majority of patients with conditions other than COVID-19, including cancer, dementia and respiratory diseases, being cared for and dying in the community<sup>6</sup>. What isn't yet clear is whether these people and their families received the care and support they needed, at a time when community services were under immense pressure. By 2040, the proportion of people dying at home or in a care home is predicted to rise to two thirds – providing that the capacity of community services is increased, with only a third of people dying in hospital<sup>4</sup>.

To ensure everyone has the care and support they need at the end of life, Hospice UK is calling on the next Scottish Government to:

## 1. Commit to a new national plan for palliative and end of life care for Scotland that puts tackling inequalities at its heart

There is only one chance to get care right when someone is dying. Access to high quality care at the end of life, where people are treated with respect, dignity and compassion and are fully involved in decisions about their care, is fundamental to a society based on human rights. Care which goes badly at the end of life can have a profound impact on individuals, their family and loved ones, leaving people at crisis point and prolonging and complicating their grief.

Currently, too many people are missing out on the care they need. People with diagnoses other than cancer, those over the age of 85, those that live alone, those from black, Asian and minority ethnic communities, those who identify as LGBTQ+ and those from deprived communities are all less likely to access palliative care<sup>7,8,9,10</sup>. For the increasing number of young people living into adulthood with a life-shortening condition, the transition from children's services to adult services can be particularly challenging. It is not acceptable that where you were born or who you are should impact the care you receive when you die. Everyone who can benefit from palliative care should have timely access to high quality, seamless care, when and where they need it.

As the number of people needing palliative care is increasing in Scotland, and more people are being cared for at home or in a care home, we need to plan ahead to ensure that everyone – regardless of their age, background, diagnosis or place of care – has the support and care they need at the end of life. As a priority, we need to ensure we have a multi-disciplinary workforce that has the capacity and skills to meet increasing demand, particular in the community. We must also better understand people's experiences at the end of life and work across all sectors and with our local communities to understand and address why some people are not receiving the support they need.

With the end of Scotland's current strategic framework for palliative care rapidly approaching, we must renew Scotland's commitment to tackle inequalities and ensure everyone receives the care they need at the end of life. This must be backed up by a robust evidence base, strong strategic leadership, and clear measures and accountability of progress.

### **The next Scottish Government should:**

- Commit to a new national plan for palliative and end of life care in Scotland which puts tackling inequalities at its heart
- Build a robust evidence base around inequalities in palliative care and lead a whole-systems approach for planning to meet future need, particularly in the community
- Commit to a national clinical lead for palliative and end of life care and ensure there is a local strategic lead for palliative and end of life care in each Health and Social Care Partnership/Health Board area
- Require Health and Social Care Partnerships/Health Boards to report on progress in delivering palliative and end of life care against nationally agreed indicators

### **2. Plan for, invest in and develop the infrastructure for bereavement support for everyone who needs it, including building capacity and resilience within local communities**

Bereavement is a life-changing experience. For most people, the support of family and friends will help them through but for some people extra help is needed. Bereavement support encompasses everything from informal befriending schemes and local community groups, to dedicated online forums and more formal one-to-one counselling sessions.

An estimated 290,000 people in Scotland are bereaved each year<sup>11</sup>. The COVID-19 pandemic will sadly have increased this further and has brought into sharp focus the toll that bereavement can have on people's lives. Between 10-20 per cent of bereaved people will experience prolonged grief<sup>12</sup>. This means grief that is debilitating, does not recede and is more likely to impact someone's health and wellbeing.

Research found that a quarter of bereaved people in Scotland who wanted support were unable to access it, because they didn't know how, felt uncomfortable asking for it or couldn't get the type of support they wanted<sup>13</sup>. Good bereavement support is fundamental to a society based on dignity and human rights. Scotland's Bereavement Charter<sup>14</sup> is an important step in describing what good bereavement care and support looks like and the difference it can make to people. Now we need to embed and promote this across all settings and society, and ensure that people can access the bereavement support that best meets their individual needs, whenever they may need it.

### **The next Scottish Government should:**

- Map current service provision of bereavement support across Scotland

- Commission research to understand bereavement need at a population level in Scotland and explore the barriers that prevent people accessing the bereavement support they need
- Develop a national plan for bereavement support in Scotland, which addresses the capacity and resilience of local communities as well as more formal bereavement services
- Invest in and develop the infrastructure for bereavement support for everyone who needs it, including building capacity and resilience at a local level

### **3. Ensure that social care support is proactive, flexible and responsive to meet the changing needs of people living with terminal illness**

People with a terminal illness deserve to live as fully and independently as possible to the end of their lives, however long that may be. To do this, they often need support from social care services, to help wash, dress and go about their lives. With progressive conditions, care needs can rapidly change. Someone with Motor Neurone Disease, for example, can quickly go from requiring one carer twice a day, to needing two carers visiting four times a day.

The current social care system is driven by cost, not quality, and has created a system that is too slow and clunky to meet people's care needs or to respond quickly when they change. Staff are overstretched and 15 or 30 minute visits are too short to provide the full extent of care that people need. The use of direct payments through self-directed support has the potential to give people much more control over what their social care support looks like and how it is delivered. However, it is not currently working well for people with terminal illness – direct payments are taking up to a year to set up and people are often not even offered it as an option.

Without the right social care support, people can quickly reach crisis point. Nearly half of carers reported that the person they cared for, with a terminal illness, had an emergency admission to hospital in the last 12 months<sup>15</sup>. Over a quarter of these carers felt that this could have been prevented if the person they cared for had received more support<sup>15</sup>.

To allow people with palliative care needs to live life to its fullest, we need a social care system that is proactive, flexible and responsive, and delivers joined up care that fully supports them, and those closest to them, when they need it most.

### **The next Scottish Government should:**

- Overhaul the commissioning of social care so that it is focused on quality and outcomes for people, not cost
- Ensure that people with palliative care needs have fast access to social care that is proactive, responsive and flexible as their needs change, including a fast-tracked process for direct payments through self-directed support
- Adequately resource, support and value the social care workforce and ensure they have the skills to meet the growing need and complexity of palliative and end of life care in the community

### **4. Increase support for unpaid (family) carers, including bereaved carers**

The impact on people caring for someone with a terminal illness is huge. The majority of carers (70%) who care for someone with a terminal illness provide over 50 hours of care a week<sup>15</sup>. A third of carers have given up work to care and almost half are struggling to make ends meet. During the COVID-19 pandemic, nearly 400,000 additional people in Scotland are now caring for older, disabled or seriously ill relatives or friends<sup>16</sup>. And as carer centres and respite services were forced to close, the burden on carers has been even greater.

It's estimated that around 40,000-50,000 carers in Scotland are bereaved<sup>17</sup>. For many when their caring role ends so does the vital support they receive from benefits and tax credits, peer support, and even their identity as a carer. This can have a significant detrimental impact on their physical and mental wellbeing. But there is currently limited support for carers once their caring role ends.

Hospice UK supports recent calls by Reform Scotland, Sue Ryder and Marie Curie to increase the support for bereaved carers in Scotland<sup>18</sup>.

### **The next Scottish Government should:**

- Ensure sustainable funding for carer centres and respite services
- Introduce a Carers (Bereavement Support) (Scotland) Bill early in the next Parliament to provide information and a plan to support carers following the end of their caring role
- Extend eligibility for the Carer's Allowance and Carer's Allowance Supplement for up to 6 months after the person's caring role comes to an end (from the current 8 weeks)

## **5. Commit to working with Scottish hospices to secure a long-term, sustainable and transparent funding solution for the charitable hospice sector**

Charitable hospices in Scotland support over 22,400 people each year, through delivering care to people in their own homes, as well as inpatient, outpatient and day hospice services<sup>19</sup>. Over 80% of the care they provide is in the community. Hospices also support families and carers, for example providing bereavement support.

During the COVID-19 pandemic, hospices stepped up as part of Scotland's response. Their expertise supported colleagues in hospitals and care homes, and they rapidly redesigned their services to support more people at home through virtual services and new community models.

On average, only a third of the cost of adult hospice care comes from statutory funding – a figure that has been gradually decreasing year on year. Hospices have to raise the remaining two thirds themselves, through fundraising and donations. The COVID-19 pandemic has devastated hospices ability to fundraise, forcing the closure of charity shops and cancelling fundraising events. Hospices welcomed the short-term funding received from Scottish Government during the pandemic. However, COVID-19 will have a long-term and far-reaching impact on the sustainability of the sector. With a growing need for the vital services hospices provide, there has never been a more pressing time to ensure a long-term funding solution for the sector.

### **The next Scottish Government should:**

- Commit to working with Scottish hospices to secure a long-term, sustainable and transparent funding solution for the sector

# About Hospice UK

Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

## About palliative and end of life care

Palliative care aims to improve the quality of life and wellbeing of adults and children with a life-shortening or terminal condition. It helps people live as fully and as well as they can to the end of their lives, however long that may be and in whatever setting they are living.

It is provided by multi-disciplinary teams who provide expert support that places equal emphasis on someone's clinical, physical, emotional, social and spiritual needs. Good palliative care also supports family members and loved ones throughout a person's illness and into bereavement.

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