



# Hospice care in Scotland 2018

Briefing document

# Acknowledgements

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- Accord Hospice
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Specific advice should be sought from professional advisers for specific situations.

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# Introduction

This briefing presents an overview of the care and support provided by charitable hospice services in Scotland in 2017-18.

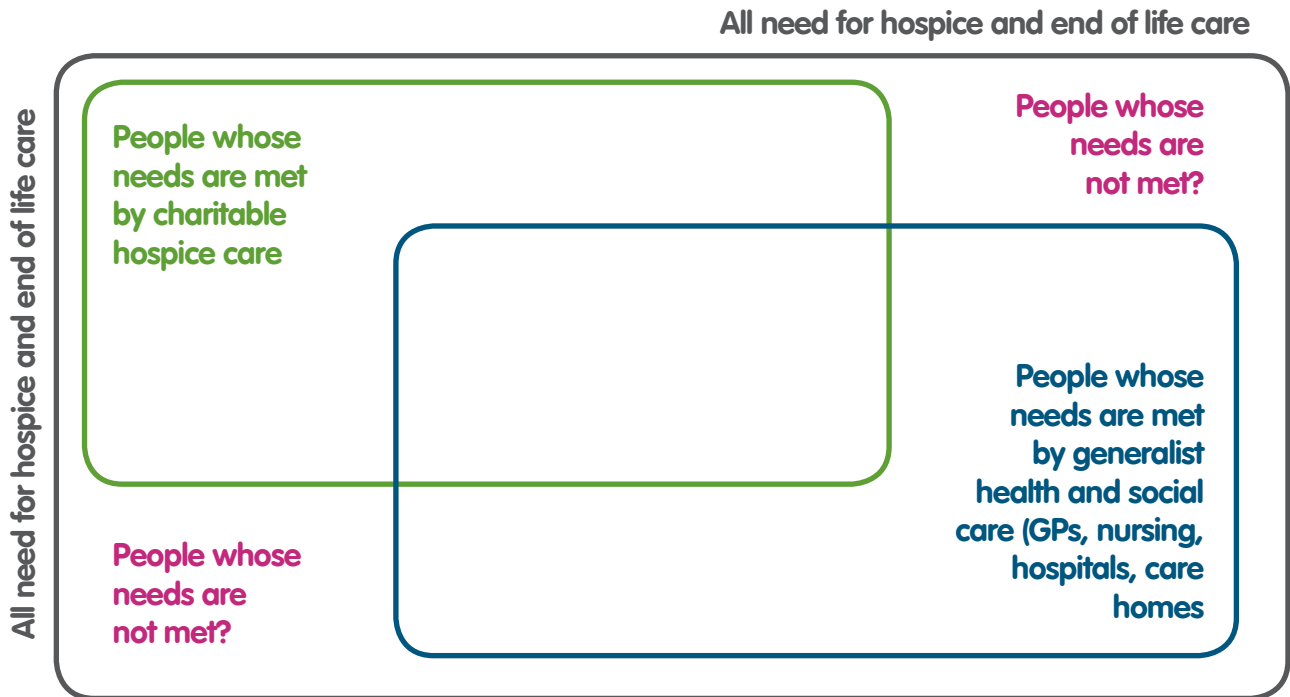
Charitable hospices in Scotland provided care and support to over 20,000 people in 2017-18. The vast majority of people received hospice care in their own homes or in a community setting. Scottish hospices also played a significant role in supporting other health and care providers to deliver palliative and end of life care across a wide range of care settings.

## Meeting current and future need for hospice and palliative care

Understanding and identifying who needs hospice or palliative care is a complex process. Because there is no regular robust assessment of palliative and end of life care need, we do not have an exact picture of how many people, or which people, in Scotland require such care each year. Instead, we must rely on population level estimates.

Almost 58,000 people died in Scotland in 2017<sup>1</sup>. Estimates suggest that three-quarters of these, approximately 43,400 people each year, could benefit from palliative and end of life care<sup>2</sup>. It is estimated that potentially one in four people who could benefit from palliative care, do not receive it<sup>3</sup>. This equates to about 10,900 people in 2017-18.

Figure 1: Need and unmet need for expert palliative and end of life care



In Scotland, the proportion of older people in the population is increasing and the number of people dying each year is predicted to rise to 61,600 by 2037<sup>4</sup>. In addition, there is an increasing number of people living with multiple conditions. This means that in the near future, more people in Scotland are likely to need palliative and end of life care, and need that care for a longer period.

# What type of care do charitable hospices provide?

Scottish hospices provide a broad range of services that deliver care and support to people with terminal and life-shortening conditions, their families and carers. The majority of the care hospices provide is focused in people's own homes and the community. In Scotland, during 2017-18:

- 88 per cent of hospices delivered care to people in their own homes
- all hospices provided a day hospice service
- nearly two-thirds (65 per cent) of hospices provided an outpatient service
- all hospices offered inpatient services, with a total 246 adult inpatient hospice beds and 16 beds for children
- almost all hospices (94 per cent) provided bereavement support
- 82 per cent of hospices had an out of hours or crisis service, through a rapid response or telephone advice line for patients and carers, or clinicians
- nearly two-thirds (60 per cent) provided a befriending service or compassionate community initiative
- nearly half (47 per cent) provided other services, including specialised legal advice, benefits support, housing advice and arranging social care assessments and packages.

# How many people receive care and support from Scottish hospices?

Scottish hospices provided care and support to over 20,000 people in 2017-18. This includes direct care to nearly 17,900 people with terminal and life-shortening conditions (41 per cent of all people estimated to need such care in Scotland) and bereavement support to over 2,300 people. In addition, Scottish hospices supported a further 1,700 people in their local community, through befriending services and compassionate community initiatives.

The vast majority (81 per cent) of people receiving care from hospices, received that care in the community, either in their own home, outpatient clinics or in day hospice care.

In Scotland, during 2017-18:

- nearly 13,000 people received hospice care in their own homes during 59,300 home visits
- 1,475 people received care through outpatient appointments
- over 1,500 people were supported through day hospice services
- nearly 3,900 people were admitted to hospice inpatient services.

# Supporting people across care settings

Scottish hospices play a vital role in supporting other care providers to deliver palliative and end of life care across a wide range of settings, including care homes, hospitals, primary care, prisons and homelessness services. Hospices provide direct patient care, give advice to clinicians and care staff, and provide training and education. In Scotland, during 2017-18:

- 88 per cent of hospices provided training and education to health and social care professionals, including GPs, hospital clinicians, community teams, care home staff, and students
- two-thirds of hospices (65 per cent) provided a 24/7 out of hours telephone advice line for clinicians
- 88 per cent of hospices provided services or support to care homes
- 82 per cent of hospices provided services or support to acute hospitals
- half of adult hospices provided services or support to prisons and nearly half (44 per cent) supported homelessness services
- two-thirds (65 per cent) of hospices provided services or support to a learning disability service
- 76 per cent of hospices carried out academic research on palliative and end of life care.

## Hospice care for babies, children and young people

Children's Hospices Across Scotland (CHAS) estimate there are over 15,000 babies, children and young people aged 0 – 25 years in Scotland living with life-shortening diagnoses<sup>5</sup>. CHAS offer palliative care, family respite and support to babies, children and young people with life shortening conditions and their families. They have two purpose-built hospices in Scotland. They also have CHAS at Home teams and CHAS in Hospital teams to provide palliative care support in families' homes, communities and hospitals across Scotland. In 2017-18:

- 435 children, young people and their families were directly supported by CHAS
- 276 children and young people were admitted to hospice inpatient services
- CHAS carried out over 1,100 home visits to 151 children and young people.

The statutory funding for CHAS's services for babies, young people and children across Scotland is managed nationally through a single health board, NHS Lothian. CHAS estimate that two-thirds of children who die from a life-shortening condition are not currently known to their services<sup>5</sup>. In 2016, the Scottish Government pledged £30 million to CHAS over the next five years as part of its plans to increase investment in children's palliative care. In 2017-18, CHAS received the first tranche of this funding. In total, in 2017-18, 53% of CHAS's charitable expenditure came from statutory funding, although this will decrease in future years as they expand services to realise the ambition of reaching every family who needs their service<sup>6</sup>.

# Hospice care in Scotland 2018

## Key statistics and estimates

Figures have been rounded and include estimates where exact data were not available.



**59,300**

visits were made to people in their own homes



**94%**

of hospices provide bereavement support

**82%**

of hospices provide services or support to acute hospitals



**16**

inpatient hospice beds for children



**18,000**

children and adults received clinical care from hospice services



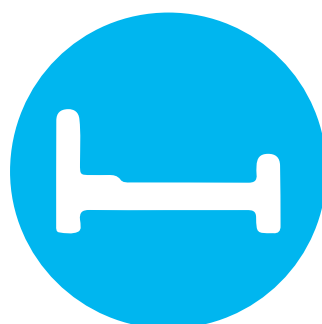
**435**

babies, children and young people received hospice care



**755,500**

hours were given by volunteers to hospices



**246**

inpatient hospice beds for adults

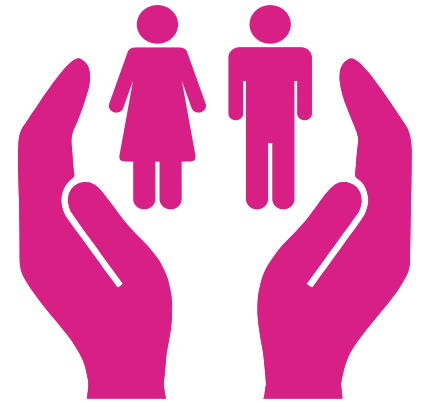
**£13 million**



Charitable spending on hospice care for babies, children and young people



**81%**  
of hospice care  
is provided in the  
community



**2,300**  
people were supported  
by bereavement care

**82%**

of hospices provide a  
rapid response, out of  
hours and/or telephone  
advice for patients  
carers and clinicians



**3,600**

adults were admitted  
to a hospice  
inpatient service

**£63  
million**



Charitable spending by all  
hospices in 2017-18\*

**13,000**

people received care in  
their own home



**88%**

of hospices provide  
education and  
training to health  
and social care  
professionals



**7,200**

volunteers donated their  
time to Scottish hospices



**76%**  
of hospices undertake  
clinical research



**3,000**

people were seen in day  
hospice and outpatient care

\*Figure does not include charitable expenditure from Marie Curie hospices.

# The palliative and end of life care workforce

Approximately 2,000 whole time equivalent staff work for charitable hospices in Scotland, with just over half providing clinical care. Hospice care is provided by a multi-disciplinary team who offer expert support that places equal emphasis on someone's clinical, physical, emotional, social and spiritual needs. Staff providing care include doctors, nurses, care assistants, physiotherapists, occupational therapists, social workers, counsellors, therapists and chaplains.

In addition to staff, nearly 7,200 volunteers provided over 755,500 volunteer hours to charitable hospices across Scotland in 2017-18. Volunteers provide support across a wide range of services: in hospice inpatient units, administration and retail, fundraising and gardening, bereavement support and compassionate communities programmes.

The Association for Palliative Medicine reports that there were 49 palliative care consultants in Scotland in 2017 (39.7 whole time equivalent posts) working across the NHS, charitable hospices and other care settings. Scotland had the lowest consultant-to-population calculation of any of the countries in the UK, at one consultant per 136,645 people<sup>7</sup>.

Hospice care providers work closely with other health and social care professionals providing palliative and end of life care in the community, including GPs, social care staff and district nurses. This workforce are facing significant recruitment and retention challenges. Audit Scotland recently highlighted the pressures faced by GPs and the primary care team, and the need for better planning to meet rising demand on services<sup>8</sup>. District nursing has the highest vacancy rate across all areas of nursing<sup>9</sup> and social care services are also facing significant and increasing vacancy rates, particularly in care at home services and care homes for older people<sup>10</sup>.

# The policy context for hospice and palliative care

The Scottish Government's vision is for everyone who needs it to have access to palliative and end of life care by 2021, regardless of age, gender, diagnosis, social group or location. In addition, the Scottish Government committed, in 2016, to doubling the provision of palliative and end of life care in the community by 2021. Charitable hospices in Scotland are a significant provider of palliative and end of life care and are central to delivering the Scottish Government's strategy.

The Scottish Government must increase its pace if it is to realise its commitments for palliative and end of life care. Integration authorities must ensure that palliative and end of life care is a priority in their population needs

assessment, strategic planning and delivery of services. This needs to be supported by a stronger evidence base on where there is need, unmet need and inequalities in accessing palliative and end of life care, and a means of measuring progress, both nationally and locally. There needs to be meaningful engagement with all partners delivering palliative and end of life care, including hospices, together with long-term, integrated workforce planning across health and social care has to meet the growing need for palliative and end of life care across Scotland.

## Funding of charitable hospice care

Since the introduction of health and social care integration in 2016, Scotland's 31 integration authorities have been responsible for palliative and end of life care for adults, including care delivered by hospices. Charitable hospices receive a proportion of their funding from statutory sources, which is determined and provided at integration authority level (previously through health boards).

The majority of their income comes from charitable donations and fundraising activities, such as retail. Without this community support, they would not be able to provide services, or deliver at the current scale. Statutory funding provided approximately 38 per cent of the

expenditure of charitable adult hospice care providers in Scotland in 2017-18, although there is significant variation between individual providers<sup>11</sup>.

# Conclusion

Charitable hospice care is an integral part of health and care provision in Scotland. It represents a wide range of local, community-based palliative and end of life care for people with terminal and life-shortening conditions, their families and carers. Hospices in Scotland are operating in a challenging environment. They face increasing financial pressures,<sup>12</sup> alongside growing demand for palliative and end of life care.

The contribution of charitable hospices is recognised and valued by local communities across Scotland. To ensure it continues to be available for people across Scotland in the future, it must be supported by sustainable funding that enables services to meet the growing and changing needs of their populations.

# Methodology

The data is collated from Hospice UK members in Scotland. This includes all 14 charitable hospice care providers supporting adults and Children's Hospices Across Scotland (CHAS) services for babies, children and young adults. It also includes data from Marie Curie's nursing service in Scotland<sup>13</sup>.

Hospice UK sent a quantitative questionnaire to Scottish members in summer 2018. The questionnaire asked about their services and numbers of people seen in these services in 2017-18. This report is based on the aggregate findings of that questionnaire, and other publicly available information and data, such as hospice websites, annual reports and other referenced sources.

A key challenge in understanding the data is the lack of individual identifiers of people using services across hospices. Therefore, while most responses distinguished between new, continuing and re-referred patients, we are unable to entirely de-duplicate the data

where a person used multiple service types. We do not know the prevalence of individuals using more than one service type or provider. Therefore, the calculation of the total number of people receiving direct care from Scottish hospices may include a proportion of double counting.

Where exact data was not available estimates have been used, or data from the previous year.

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