



# Hospice Care in Wales

Activity and need

# 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.

## What is hospice care?

Hospice care aims to improve the quality of life and wellbeing of adults and children with a life-limiting 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.

Hospice care looks after someone's physical, emotional, social and spiritual needs. This means that hospices provide a wide range of services.

You don't have to stay at a hospice to access their care - in fact many people receive support from a hospice whilst they are living at home or in a care home.

This approach to care also supports family members and others close to the person who is receiving hospice care. This support is offered during a person's illness and into bereavement.

In Wales, each hospice has evolved to meet the particular needs of its community as an integral part of the health and care system, including by working in partnership with the NHS and social care providers.

Hospices aim to provide seamless care by working alongside GPs, district nurses and social care workers. They also provide training and advice to other health and care professionals and contribute to making Wales a compassionate country by mobilising communities to support people affected by death, dying and bereavement.

### Palliative care

Palliative care takes a holistic approach to treatment and care for people with a life-limiting or terminal conditions and their families.

### End of life care

End of life care is a part of palliative care and usually refers to care given in the last year of life.

# Funding hospice care

Hospice care is free at the point of access for all who need it but reliant on the goodwill of communities to sustain it.

Hospices in Wales receive a total of £5.7 million annually from statutory sources. This is in comparison with the £33.3 million they fundraise each year<sup>1</sup>.

Since 2009 health boards have funded core clinical roles in adults' hospices based on a formula that aimed to ensure equal access to a specialist workforce on a per capita basis. This funding arrangement has not been reviewed to reflect demographic changes or the changing nature of palliative and end of life care.

There is no equivalent statutory funding distribution for children's hospices in Wales. As a UK trend, children's hospices receive significantly less statutory funding as a proportion of their total expenditure than adults' hospices<sup>2</sup>.

# Hospice care in Wales 2019

## Key statistics

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



**12,700**

people were cared for by hospices in Wales

**19,500**

nights of care in adult hospice beds



**90%**

of care for adults is provided in the community



**3,700**

people volunteered their time



**2,700**

people were supported with bereavement care

**1,000**

short breaks were provided for children



**59,500**

visits were made to people in their own homes



**£33.3 million**

fundraised each year



# Palliative care need now and into the future

## Death and dying in Wales

Taking the five year average, around 33,000 people are expected to die each year in Wales.

This is set against the backdrop of current projections of population and mortality trends, which suggest that **the number of people dying in Wales is set to increase by 25 per cent by 2040<sup>3</sup>**.

## Palliative care need for adults

Of those who die each year in Wales, around **four out of every five adults will have died with a condition**, such as dementia, cancer, heart disease or respiratory diseases, **that could benefit from taking a palliative care approach<sup>4</sup>**. That equates to an estimated 26,500 adults with a palliative care need under current population figures<sup>5</sup>.

Of these, **hospices in Wales reach 12,000 adults annually** through the provision of specialist palliative care for people and their loved ones.

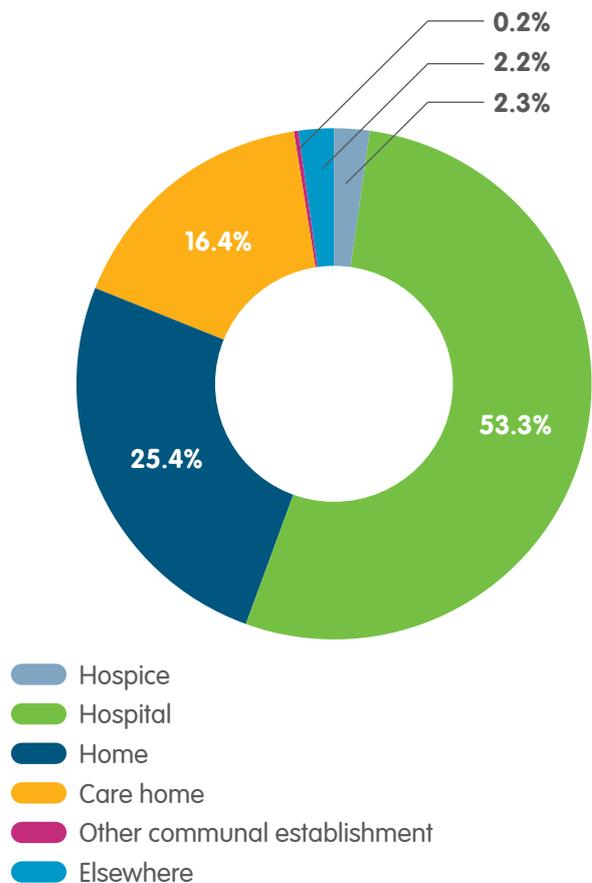
**Palliative care need is projected to increase by 42 per cent over the coming two decades.** This projected change is driven by a sharp increase in the anticipated number of people dying from conditions such as dementia and cancer and from our ageing population, whereby more than half of all people who die in 2040 are projected to be aged 85 or over<sup>6</sup>.

## Place of care

While people's preferences and choices for their end of life care will vary dependent on their personal journey and circumstances, around 70 per cent of people say they would like to die in the place they call home<sup>7</sup>.

This is in comparison with the general trend in Wales where more than half of all deaths occur in hospitals and a quarter of people die in their own homes. Sixteen per cent of all deaths in Wales occur in care homes<sup>8</sup>.

## Place of death



A significant proportion of people who die in the place they call home – whether that is in their own private home, a care home or another communal establishment – will be supported by hospice at home and hospice community teams. In addition to this, two per cent of people will be cared for as they die in hospice inpatient units, which for many is their preferred place of care.

No matter where the person's final place of care, a significant proportion of hospice care

involves care that enables the person to remain in their usual place of residence for as long as possible. That is why **90 per cent of hospice care in Wales is delivered in the community**. This incorporates outpatient clinics and day hospice services as well as community and hospice at home care, which contribute to around **59,500 home visits each year**.

## Babies, children and young people

In Wales there are around 3,600 children with a life-limiting condition<sup>9</sup>. Of these, an estimated **1,000 children will have a palliative care need** at any given time and sadly around 200 children will die each year<sup>10</sup>.

**Children's hospices in Wales are reaching around 470 children and their families each year.** This includes both specialist end of life care for a small number of children and longer term, family-centred and therapeutic care for a greater number of children with life-limiting conditions and their families, which may extend over a period of years. Central to the children's hospice offering is the provision of specialist respite care for children and their families. Each year children's hospices across Wales provide around **1,000 short breaks**.

## Bereavement support for families and carers

For each person who dies, there will be five people on average grieving. Care for families and carers is central to the hospice offering and this extends to providing appropriate bereavement care. Each year, hospices in Wales provide pre- and post-**bereavement care to 2,700 people**, which includes **care for 700 children bereaved children**.

## Unmet need and unequal access to care

Unmet and under-met need for palliative care includes those people who miss out on palliative care entirely; people who do not have their care preferences met, including where services are less accessible for them because of identity, cultural or protected characteristics; and those people who are not able to access palliative care early enough to fully benefit from this care.

Estimates of unmet need for palliative care indicate that **one in four people are missing out on the right palliative care**<sup>11</sup>. In Wales, this equates to an estimated **6,625 people with an unmet palliative care need each year**. While hospices are reaching more than 12,700 each year, there remains a significant number of people who are not reached by palliative care services.

There is widespread recognition that access to palliative care is unequal and that some groups are less likely to have their palliative care needs met than others<sup>12</sup>. People who are known to be under-represented in specialist palliative care referrals are people aged over 85, people from BAME backgrounds, people who identify as LGBTQ+, homeless and imprisoned people<sup>13</sup>.

**Hospices, along with statutory partners across the health and care landscape, have a role to play in meeting both the increasing need for palliative care into the future but also to address the gaps in current identification of palliative care needs.**

**Realising the hospice ambition of caring for more people and families affected by death, dying and bereavement is entirely reliant on communities who both fundraise and volunteer for their local hospices as well as the continuation of necessary statutory funding.**

# Hospice care in Wales: key statistics and estimates (2018-19 activity)

<b>12,700</b>	Total people supported by hospices
<b>12,000</b>	Adults cared for directly by hospices
<b>10,750</b>	Adults cared for in the community
<b>59,500</b>	Home visits
<b>9,150</b>	Adults care for by community care and hospice at home
<b>1,300</b>	Adults cared for in hospice inpatient units
<b>95</b>	Adult hospice beds
<b>19,500</b>	Nights of care
<b>1,800</b>	Adults cared for in day hospice and outpatient care
<b>90%</b>	Care delivered in the community by adults' hospices
<b>470</b>	Children cared for by hospices
<b>17</b>	Children's hospice beds
<b>1,000</b>	Short breaks
<b>4,300</b>	Nights of short break care
<b>86%</b>	Families supported in the community as well as the hospice by children's hospices
<b>2,700</b>	People receiving bereavement care
<b>700</b>	Children receiving bereavement care
<b>3,700</b>	Volunteers
<b>296,000</b>	Hours contributed by volunteers
<b>£39.1 million</b>	Annual expenditure
<b>£5.7 million</b>	Annual statutory contributions
<b>£33.3 million</b>	Fundraised annually

# Methodology

This report draws on national data sets and hospice activity data during 2018-19 to build a picture of hospice care in the wider context of death, dying, bereavement in Wales.

The Covid-19 pandemic will inevitably have changed the delivery of hospice care and the need for palliative care in Wales during 2020. Hospice UK will seek to report on activity in 2020 and beyond when accurate data for this period becomes available.

Hospice UK collected activity data for the period April 2018-March 2019 from charitable hospices across Wales using a survey and ad hoc requests. The activity data sought was based on the now ended Minimum Data Set (MDS) for Specialist Palliative Care Services and adapted to capture activity data from children's hospices. There was a response rate of 87%, or 13 of 15 hospices.

Where accurate activity data was not available, an estimate of activity was made using a combination of reported activity in hospice annual reports and previous years' activity data. The figures in this report are based on the aggregate findings of this data. As such, the figures presented in this document about numbers of patients and levels of service use should be considered estimates rather than exact counts.

A key challenge in understanding hospice service activity data is the lack of individual identifiers to see where people use more than one service type. We do not know the prevalence of individuals using more than one service type, such as people who access inpatient care or hospice at home services who also access hospice day services and outpatient care. Adjustments have been made to minimise the impact of accounting for individuals accessing more than one hospice service based on the service model of each hospice and the activity data available.

All calculations have been made based on the information available to Hospice UK from hospices in Wales at the time of writing and other published sources as referenced in the document.

This report is not intended to be used for year-on-year comparison with previous data collection with Hospice UK members in Wales. Variations in figures can be accounted for by the availability of different data and changes in the survey questions.

# Acknowledgements

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- Paul Sartori Hospice at Home
- Severn Hospice
- Shalom House
- Skanda Vale
- St David's Hospice
- St David's Hospice Care
- St Kentigern Hospice
- Tŷ Gobaith/Hope House Children's Hospices
- Tŷ Hafan
- Tŷ Olwen Trust

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