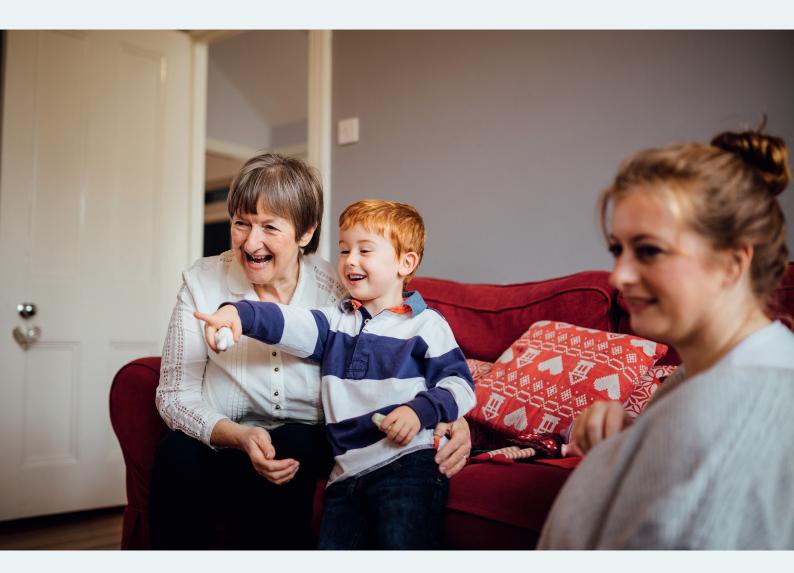


# Hospice care in Wales 2018



Supporting people closer to home: meeting the challenge now and into the future

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### Forewords

Charitable hospices across Wales continue to go the extra mile for the adults, babies, children and young people they support. In providing most of their care to people in their own homes Welsh hospices are ahead of the curve compared to other parts of the UK. A growing body of evidence indicates that this is better for people needing care, their communities and health services. In an ever changing world, and as demand for hospice care increases, I am pleased to see innovation at the heart of Welsh hospice care, continually finding new ways to support people, their families and communities affected by life limiting and terminal conditions.

#### Tracey Bleakley, Chief Executive, Hospice UK

Hospices are their communities. As well as providing direct care to more than 11,400 people and their families annually, Wales' 16 charitable hospices reach thousands more through their community engagement and development. We can mobilise our communities to find local solutions to the needs of our populations and have the agility to respond quickly when that need arises.

Hospices are also part of their health and care communities and work in partnership with our colleagues across the sector to deliver the right care, at the right time, in the right place. Building on our experience, we must continue to collaborate and evolve if we are to meet increasing needs for hospice care and to deliver more of that care in the community and closer to home.

#### Trystan Pritchard, Chair, Hospices Cymru

### What is hospice care

Hospice care seeks to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal illness, helping them live as fully as they can for the precious time they have left. It aspires to be accessible to all who could benefit and reflect personal preferences and needs.

Hospices in Wales are rooted in their communities and are shaped by the communities they serve. Each hospice has developed to reflect the needs and the context of its local area in terms of its people, its geography, and the local health system. Terminal and life-limiting conditions where a hospice and palliative care approach may be beneficial include frailty, dementia, heart, liver and renal failure, respiratory conditions such as chronic obstructive pulmonary disease (COPD), neurological conditions such as motor neurone disease, and cancer.

Charitable hospices in Wales provide expert care for those in need, and their family and carers, and care is free at the point of access.

### Who needs hospice care?

Understanding and identifying who needs hospice or palliative care, from generalist to specialist, is currently a complex and inexact process. This means that we do not have an exact picture of how many people, or who they are, in Wales who need such care each year. Instead, we need to rely on population level estimates.

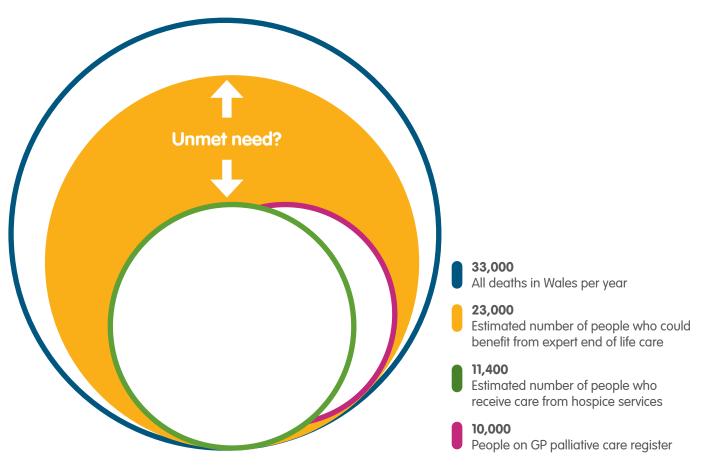
Each year around 33,000 people die in Wales.<sup>1</sup> The Welsh Government and NHS Wales' strategic planning for palliative care, the 'Palliative and end of life care delivery plan 2017-2020', is based on an estimate that 70 per cent of all deaths, some 23,000 people per year, could benefit from hospice or palliative care.<sup>2</sup> More recent estimates of need place this figure higher at between 74 per cent and 96 per cent of all deaths. Taking the middle of these two points, 85 per cent, would mean 28,000 people per year in Wales could benefit from hospice or palliative care, over 20 per cent more than the current Government estimate.<sup>3</sup>

### Identifying unmet need

Data is not currently available to assess the total number of people in Wales who have received the right hospice or palliative care, delivered by the right services, at the right time. This is because data at a national level is held on the total number of people who receive specialist palliative care, and separate data on the total number of people who are known to their GP as needing palliative care, but it is not possible to cross reference these at an individual level.

Current estimates of unmet need have been placed as high as one in four people missing out on the care they need.<sup>4</sup> However, without greater clarity on who is being cared for, where, and by whom, it is impossible to accurately determine whose needs are not being met. Despite this, we do have indications on how we might locate people whose needs are not being met. For example, although hospice and palliative care is appropriate for people with a range of terminal and life-limiting conditions, people with diagnoses other than cancer continue to be under-represented in referrals to specialist hospice and palliative care than people with cancer. While cancer accounts for just over a quarter of all deaths (28 per cent),<sup>5</sup> 90 per cent of people who were cared for in a hospice inpatient setting in Wales had cancer, and 76 per cent of people who were cared for by community advisory and hospice at home services had cancer.

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



### Children and young people

It is not only adults who will need hospice and palliative care. Babies, children and young people with life-limiting conditions also need hospice and palliative care support, often over a number of years and potentially into young adulthood. Understanding the level of need in babies, children and young people is more complex than for adults.

At any given time, an estimated 1,050 children and young people will have a palliative care need;<sup>6</sup> of these, around 10 per cent, or 105 will die each year. The Welsh Government estimates that there are 3,200 children across Wales who have a life limiting condition.<sup>7</sup> These figures do not include neonatal palliative and end of life care. While absolute numbers of children and young people are vastly lower than adults, the level of complexity of care and the overall needs of the family are generally far greater.

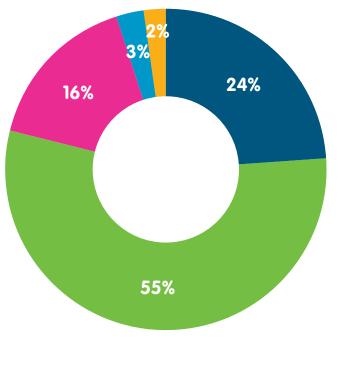
For children and young people, there is no central register identifying those with palliative care needs. Even more so than for adults, children tend to have contact with a range of statutory and voluntary services from across health, social care and education. Often these diverse professionals may not recognise that the child could benefit from a palliative care approach or from expert support from a children's hospice over the longer term, making it difficult for children's hospices to reach all children who could benefit.

## Where can people access specialist hospice and palliative care?

Across Wales there are 16 charitable hospice providers offering a wide range of services to people in their homes, in day services or outpatient clinics, into care homes and hospitals, and through inpatient hospice care. The majority of care provided is to people in their own homes or attending the hospice, rather than just inpatient care. Health professionals will make referrals to these providers. Improving access to care will include supporting such professionals to widen their sense of who might benefit from hospice and palliative care, and refer accordingly. In addition to the care provided by hospices, people with terminal and life-limiting conditions may also be supported by specialist palliative care teams within the NHS, disease specialists who have training in palliative care, or by primary care practitioners with palliative caring skills, such as GPs. Clinical nurse specialists and district nursing services are central to the provision of both specialist and generalist care.

More than 50 per cent of deaths in Wales occur in NHS hospitals.8 Hospital will be the appropriate place of care for some, either out of choice or through clinical need. Across the UK the percentage of deaths occurring in hospital has been decreasing over time, but this trend is slow and indicates that hospital will continue to be the place where half of all deaths will occur. For many, however, an admission to hospital at the end of life will be counter to their care preferences<sup>9</sup> and clinically unnecessary. Meeting people's needs at end of life will include increasing the numbers of people who die in their preferred place of care, as well as ensuring that people are able to have a good death regardless of setting.

#### Figure 2: Deaths in Wales - place of death\*



#### Virtual reality and 360°

Working with Velindre NHS Trust, Marie Curie Hospice Cardiff & Vale are developing virtual reality technology to support people in a hospital setting, and their families, to improve the experience of people being transferred from hospital to the hospice at the end of life. A virtual reality tour and 360° images of the hospice have been developed and piloted which allow patients and their families to explore the environment prior to admission.

### Wales' first Hospice in a hospital

St David's Hospice will be launching the first Hospice in a hospital in Wales in Spring 2019 as it opens a satellite unit at a community hospital in Holyhead. This will address the current inequalities in hospice care across North West Wales where the only hospice beds are located in Llandudno, a significant distance from the communities of Gwynedd and Anglesey. Working in partnership with Betsi Cadwaladr University Health Board, which is providing the space, St David's will manage and staff a 4-bed inpatient unit with full hospice services delivered by a specialist clinical team.

\*ONS Mortality Statistics 2016 as commissioned by Paul Sartori Foundation



Home

Hospice inpatient unit

### Meeting changing needs

#### Ageing population

Wales's population is ageing; the Welsh Government's 'Future Trends Report' highlights that the number of people aged over 65 is set to be 40 per cent higher by 2039 than in 2014.<sup>10</sup> With people over 65 accounting for 85 per cent of all deaths,<sup>11</sup> hospices are likely to see a greater volume of people with end of life care needs by the end of this period. Hospices are also likely to see older people presenting with more complex needs as they approach the end of life; combined with the greater prevalence of life-limiting conditions such as cancer and dementia amongst older people, an estimated nine per cent of the population will have an age-related long-term illness by 2030.12

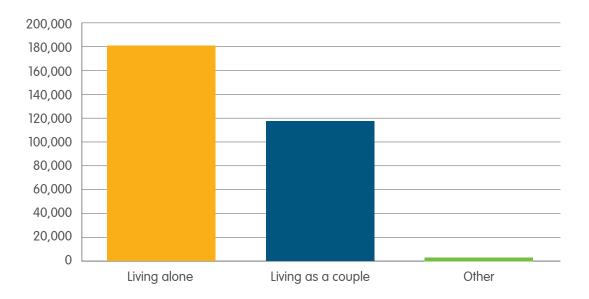
#### Planning for the nation's future

The Welsh Government has a central role to play in planning for a Wales that meets the health and care needs of its population now and into the future. It set out its vision of a transformed and sustainable health and care service in 'A Healthier Wales', where care is primarily delivered closer to home and in the community while admission to hospital is reserved only for acute need.<sup>13</sup> With the majority of people with palliative care needs – both adults and children – expressing a preference to be cared for at home as long as possible, hospices have a crucial role to play in realising this vision.

### Supporting hospices to meet the challenge

There is a need for a stronger understanding of population change in order to develop the right care for the future. PopNAT, Hospice UK's population-based needs assessment tool,<sup>14</sup> supports hospices, local decision makers and other service providers across health and social care to plan for the future, identify unmet need and to innovate services based on intelligence about the local population. Using this tool to understand the characteristics of current populations can help illuminate some of the challenges hospices will need to address to meet greater need for hospice care, with more of that care being delivered at home or in the community.

As an example, understanding levels of living alone in older age is essential to developing a picture of need.



#### Figure 3: Living arrangement of persons aged 65 years plus in Wales (Census 2011)

People who live alone are known to be less likely to achieve their preferred place of care and death than people who live with a partner or family.<sup>15</sup> This is often because a dying person requires a significant amount of care and support around the clock. The last Census shows there were 178,334 people over 65 living alone in Wales – a figure which is likely to increase as the population ages. While the majority of these people will be leading relatively healthy lives, a significant proportion will have health and care needs and some will be in their last years of life. To meet future need health and social care planners, in the Welsh Government, local government, the NHS and hospice care, will need to consider how to support greater numbers of people living alone who wish to be cared for at home, including by providing support to carers within the community.

### Hospice care in Wales 2018 Key statistics and estimates





### Hospices in their community

#### Community care and hospice at home

Key facts:

- 90 per cent of hospice care in Wales is provided in the community, where people either receive care in their home, or attend day hospice our outpatient services
- more than one third of adult hospices in Wales are entirely community based, meaning they have no inpatient services.

Hospice boundaries extend well beyond the hospice walls, reaching out into their communities. Community, day hospice and hospice at home services account for 90 per cent of all adult hospice care in Wales.

In 2017-18, hospice at home and community services supported more than 10,000 adults, bringing hospice care to people in their home or enabling people to remain in their own home through day hospice and outpatient care. Charitable hospices do not do this alone; it takes a wide range of NHS and other services to make this work, from domiciliary and social care providers, to GPs and district nurses.

#### Day hospice and outpatient care

Key facts:

- 2,150 adults supported in day hospice and outpatient clinics
- All charitable hospices provide therapeutic care, such as physiotherapy, art therapy, occupational therapy, and more
- All charitable hospices provide complementary therapies for patients and carers
- 38 per cent of hospices have resident art, music or play therapists

Hospice buildings are not just for hospice beds. In 2017-18 2,300 adults were supported in day hospice or outpatient clinics, enabling them to receive specialist palliative care while remaining in their own homes.

Outpatient and day hospice services may include:

- Disease-specific or symptom-management clinics with input from consultants and clinical nurse specialists
- · Physiotherapy and occupational therapy
- Complementary therapies (for patients and their carers)
- Art, music and play therapies
- Carer's needs assessments and support

#### **Inpatient care**

Key facts:

- 97 adult inpatient hospice beds
- 1,400 adults admitted to in inpatient services
- 22,500 overnight stays in charitable hospices

Providing a 'home from home' with specialist medical care available around the clock continues to be a mainstay of hospice care. Offering an alternative to hospital for those people who do not wish, or are unable, to die at home is a vital service offered by hospices with inpatient facilities. Some people may choose to die in the hospice because being cared for at home is unsuitable, while others will recognise the hospice as a peaceful, joyous location in which to spend their final days.

#### **Bereavement support**

Key facts:

- More than three quarters of charitable hospices provide bereavement support
- 2,300 people received bereavement care through charitable hospices

Psychological and emotional support is a crucial part of the holistic care provided by both adult and children's hospices. This includes support for the person and their family and carers to prepare for an approaching death, and support for bereaved families as they adjust to life after the death of a loved one. Bereavement support can range from specialist one-to-one bereavement counselling to more informal volunteer-led support groups, such as singing, knitting or walking groups.

#### Social work and welfare rights

Death and dying are social phenomena that affect a person's whole social network, the way they live and work, and their own and family's finances. For this reason, hospices across Wales employ social workers and welfare rights officers, or work in partnership with other third sector organisations, to support people to claim their entitlements and to ensure their housing and environment is suitable to their needs.

## Hospice care for babies, children and young people

Key facts:

- 800 children and their families supported by children's hospices
- 350 children and their families supported through inpatient hospice care
- 1,400 overnight stays in children's inpatient care, including short breaks and respite care
- 17 children's inpatient hospice beds

Welsh children with life-limiting conditions are supported by three children's hospices: Tŷ Hafan, serving children across south and west Wales and southern Powys; Tŷ Gobaith, serving children in north Wales; and Hope House (located across the English border), serving children in mid-Wales.

Unlike adult hospices where the vast majority of people are supported in their last year of life, children's hospices support children and families to make the most of the time they have together, which can often be over a period of years.

#### At the hospice

Therapies are central to children's hospice care; they are about developing and improving a child's function but they are also about having fun and enabling a range age appropriate experiences. These include:

- Art therapy
- Hydrotherapy
- Music therapy
- Play therapy
- Complementary therapies

Children's hospices aim to maintain wholefamily resilience and to sustain families in their caring journeys. This can mean specific support for mothers, fathers and siblings. In 2017-18 children's hospices provided 1,400 nights of overnight care to Welsh children, with 350 children and their families benefiting from this service.

#### At home

While the hospice provides expert, tailored care, with access to specialist facilities, many families prefer to receive all or part of their care in their own homes. This is especially the case for children and families who live a significant distance from the hospice building. In 2017-18 well over half (60 per cent) of children's hospice care was delivered at home or in the community, with 800 children and families benefiting from this service.

As with adult hospice care, enabling care to be delivered outside of the hospice building means working in partnership with local health and care providers. A challenge in delivering children's hospice care in the community, and particularly end of life care where hands-on care and support may be required around the clock, is the shortage of NHS community paediatric nurses across areas of Wales. The Cross Party Group on Hospices and Palliative Care in its report, 'Inequalities in access to hospice and palliative care: challenges and opportunities', recommend that the End of Life Care Board develop an action plan to address these shortages and regional variations.<sup>16</sup>

#### Working in partnership for children at the end of life

Tŷ Gobaith Children's Hospice will be leading on the delivery of all end of life care to children and young people across the north Wales region, whether they are at home, hospital or hospice, following partnership work with Betsi Cadwaladr University Health Board. Following a prognosis that a child is entering end of life, Tŷ Gobaith children's hospice will take the lead to co-ordinate a multi-disciplinary team to deliver the best possible end of life experience. Given the geography of north Wales, success will depend on a partnership approach between health board and hospice personnel. An agreement in principle to joint resourcing, rotas and tasking has been reached.

### Part of the health and care community

Key facts:

- 65 per cent adult hospices provide training for care homes
- Almost three-quarters of adult hospices provide training for GPs

Hospices work in partnership with, complement and supplement the NHS services in their local areas. The service model of each hospice varies depending on the existing NHS provision in the area, its geography and demographic profile, however every charitable hospice supports the people in its area to access a wider range of services than those provided and funded by the NHS, such as specialist bereavement care, support for carers and complementary therapies.

As third sector organisations, charitable hospices can be agile in their approach to innovating services, including by working collaboratively with the wider health and care community and trialling new ways of working in response to population need.

#### Hospice support and education for care homes

Hospice of the Valleys supports the 16 care homes in its area through a programme of outreach support, education and training, with the view to upskilling the care home workforce in the palliative care skills they need to support dying people. Evidence-based assessment tools have been introduced in the care homes to manage symptoms and a significant increase in the 'Care decisions tool at the end of life' has been seen amongst the care homes in the area in comparison with other care settings. Care homes have seen the benefit of this programme on staff retention and the hospice is now auditing its impact on hospital admissions.

Providing expert care and support for people dying at home or in a care home necessitates seamless working between hospices and social care. Hospice at home services are reliant on the round the clock domiciliary and residential care provided by social care colleagues to ensure that a person's essential personal care and social needs are met. However, with the recognition that social care funding is unsustainable in its current model – both within Wales and across the UK – people who choose to be cared for and die at home are vulnerable within a system that is seeking to curtail its services. Without adequate social care for people with palliative care needs, sustaining people in their own homes and avoiding admission to hospital is unmaintainable.

### **Communities supporting their hospice**

#### **Volunteers**

Key facts:

- 3,500 volunteers
- 290,000 volunteer hours per year
- £3.6m equivalent in volunteer time

Hospices rely on their communities to support them deliver their vital care, to keep their buildings running and to ensure that people and their families are supported in welcoming environments.

Each year, hospices in Wales are supported by more than 3,500 volunteers. Nationally, with the average volunteer spending 83 hours per year volunteering,<sup>17</sup> this equates to an estimated 290,000 hours of work contributed by volunteers delivering various aspects of hospice care. As a financial equivalent, this represents £3.6m of value added to the hospice sector.<sup>18</sup> Volunteers support hospices as:

- Day hospice hosts
- Gardeners
- Drivers
- Receptionists
- Event fundraisers
- Counsellors and complementary therapists
- Hair and beauty practitioners
- Befrienders
- Café servers

While hospices benefit hugely from volunteer contributions, volunteering is always mutually beneficial. Volunteers can benefit through a feeling of wellbeing and purpose or through the acquisition of vital skills.

#### Volunteers giving back and giving forward

City Hospice relies on volunteers with personal experience of using its services, including bereavement care, to support others. Volunteer bereavement coffee morning hosts are often former members of bereavement support groups. Developing service users through volunteering opportunities supports them in their journeys as well as sustaining the hospice's vital services.

#### Volunteers delivering palliative care and serving their community

Skanda Vale Hospice employs a Clinical Volunteer Co-ordinator whose role is to seek out individuals who are looking to be of service and make a difference to their community. 25 clinical volunteers who come from a range of backgrounds, including retired nurses and medical professionals all from the local west Wales community, have been recruited. Some volunteers are also in other employment but volunteer shifts to a community service in which people matter and time counts.

## Community development and the hospice movement: Compassionate communities

A compassionate community is a community that supports people who are ageing and dying, as well as their family and carers, and encourages others to talk openly about death, dying and bereavement. The compassionate community works alongside health and social care professionals to meet a person's holistic needs as they approach death, enabling them to be cared for in their community.

Using a community development approach, compassionate communities models marry naturally occurring supportive networks with existent community resources. Hospices, with their expertise in palliative and end of life care and their experience of mobilising volunteers, are uniquely placed as a community resource to lead on such initiatives.

### Compassionate Communities in action

Nightingale House Hospice recognised the potential benefit of developing Compassionate Communities volunteer befriending services in Corwen to complement its day unit outreach in that community. The hospice works with community-based volunteers to design, deliver and support their own local volunteer befriending services. While communities identify the right service model to meet their needs, the hospice supports by providing the necessary recruitment safeguards and induction training. During 2018 the Welsh Government declared its aspiration for Wales to become the first Compassionate Country.<sup>19</sup> This would see death, dying and bereavement acknowledged as a public health issue, with citizens informed, and contributing to, health and wellbeing promotion alongside health care services to support ageing and dying people and their families.

### **Resourcing hospice care**

Key facts:

- Hospices in Wales have a combined revenue of £36 million each year
- £5 million comes from statutory sources, such as the NHS
- Hospices in Wales have to fundraise £28 million each year to run their services

Core clinical roles in adult hospice care in Wales are funded by health boards using the Welsh Funding Formula, with the ambition of ensuring there is equitable provision of clinical resource on a per capita basis. This formula was implemented in 2009 and has not been revised since. As a total across Wales, hospices receive £5 from statutory sources, such as the NHS, the End of Life Care Implementation Board and local health boards.

With a total combined revenue of £36 million each year, charitable hospices rely on the good will of their communities – local and national – to fundraise £28 million each year to continue delivering their services. This additional fundraised money goes towards supplementing the statutory funding of clinical care as well as providing expert holistic hospice services, including bereavement support, welfare rights advice, play therapies and short breaks.

## **Opportunities: Meeting the future challenge**

#### Providing seamless care to enable people to remain at home for as long as possible

People with palliative care needs require a seamless health and care service in order to remain at home for as long as possible. New service models, where partnerships between hospices and community-based health and care providers such as care homes, domiciliary care, primary care and carers' organisations, are required if we are to see this change.

Successfully trialled service models should be recognised nationally and, where appropriate, scaled up to deliver across Wales, including through support from Regional Partnership Boards and the Welsh Government as part of the Transformation Programme.

The regional variations and shortages nationally of community nurses, including community paediatric nurses with palliative care skills, must also be addressed by the Welsh Government and local health boards if we are to realise the vision of more people cared for and dying at home.

#### Hospice and palliative care services planned and developed based on an assessment of population need

Meeting the dual challenges of providing expert palliative care to a larger number of people and supporting people closer to home is reliant on planning based on local population need. At a local level, hospices should make use of PopNAT to support planning and health boards should ensure hospices are included in the current Integrated Medium Term Planning process. Regional Partnership Boards and Public Services Boards should ensure that hospice and palliative care needs are included in forthcoming statutory population needs assessments under the Social Services and Wellbeing (Wales) Act and the Wellbeing of Future Generations (Wales) Act.

#### An established compassionate country and mobilised compassionate communities

Hospices are well placed to position themselves as instigators of local, voluntary compassionate communities projects, learning from best practice and responding to the area's needs.

At a national level the Welsh Government should strengthen its commitment to becoming the first compassionate country by outlining actions and milestones towards achieving this aim. Hospices and the WCVA have a role in facilitating the compassionate model at a national level.

### Methodology

Hospice UK undertook an online quantitative survey of Welsh hospices during September – November 2018, based on the now ended Minimum Data Set (MDS) for Specialist Palliative Care Services. The survey questions may be found at http://bit.ly/HospiceUK\_Mini-MDS2018Questions. The figures in this report are based on the aggregate findings of that survey, data from other sources (such as annual reports), and estimates where exact figures were not available. 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.

All calculations have been made based on the information available to Hospice UK from hospices in Wales at the time of publication and other published sources as referenced in the document. Where it has not been possible to obtain exact figures an estimate has been made based on comparable services or proportionate estimates. In order to maximise confidentiality and for ease of communication, figures have been rounded.

A key challenge in understanding the patient 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 hospice at home and inpatient care. Therefore, the calculation of the total number of people receiving direct care from Welsh hospices may include some double counting. To minimise the impact of duplication in calculating the total number of people receiving direct care from hospices we estimated that hospice at home and community provision accounted for 75 per cent of all provision in Wales. The figure of 75 per cent was based on the UK wide average of 67 per cent and the tendency in Wales for greater prevalence of hospice at home provision in relation to the other UK nations.

The calculation of overnight stays in adult hospices is drawn from the combined average number of days in inpatient units, multiplied by number of admissions. In calculating the combined average number of bed days we did not include Skanda Vale Hospice's figures as their inpatient model is different, and thus their average is an outlier. The calculation of overnight stays in children's hospices is drawn from the combined average number of days in inpatient units, multiplied by number of admissions.

The calculation of number of home visits is based on a Scottish sample of 5,000 patients, where the average number of home visits was 6.7 per patient. We have assumed a similar level of home visits in Wales, thus the calculation is the number of people seen in community/hospice at home services multiplied by 6.7.

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, including from additional Hospice UK members in Wales, and changes in the survey questions.

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### Acknowledgements

We are grateful to our member hospices in Wales for their support and provision of data, on which this report is based:

- Bracken Trust
- City Hospice
- Hospice at Home Gwynedd and Anglesey
- Hospice of the Valleys
- Marie Curie Hospice Cardiff and the Vale and Wales Nursing Service
- Nightingale House Hospice
- 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

While great care has been taken to ensure the accuracy of information contained in this publication, it is necessarily of a general nature and Hospice UK cannot accept any legal responsibility for any errors or omissions that may occur.

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

Written by Catrin Edwards and Kathleen Caper at Hospice UK.

We are incredibly grateful to the National Gardens Scheme for their continued support of hospice care in the UK.

Published by Hospice UK in December 2018.

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