The role of hospice care in Scotland
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What is hospice care

Hospice care seeks to improve the lives of people living with terminal and life-shortening conditions, and helps people to live as well as they can, to the end of their lives. It understands that a person’s physical, emotional, spiritual and social needs are of equal importance, and supports carers, family members and friends – through a loved one’s care, during bereavement and into remembrance.

Even at the end of our lives we have hopes and aspirations. We want to be where we feel most comfortable, do what brings us joy, and have those we love by our side. We want to be, despite everything, ourselves.

Hospice care is defined by its work to fulfil such hopes, and it is the mission of hospice care to improve people’s experience of death, dying and bereavement. It has developed over the last 50 years to provide care and support to more people, in many different settings – in hospice beds, at home, in care homes and in hospitals – and for ever more complex needs.

Summary

Hospice care in Scotland is provided by 16 charitable hospices across the country, all of which are charities that rely on the generous support of the local communities that they serve. In this report, we set out the vital contribution that hospices in Scotland make to supporting people with terminal and life-shortening conditions.

In 2014-15 charitable hospices in Scotland provided direct care to over 20,000 people, and reached many more people indirectly. This represents around 40 per cent of all people estimated to need such care. Scotland’s 16 hospices provide care and support to children and adults across people’s homes, hospitals, care homes, day hospice and hospice inpatient units. Multidisciplinary teams made up of nurses, doctors, psychologists, social workers, physiotherapists, complementary therapists, volunteers, and more, work together to support individuals and their loved ones.

Hospices are unique among charitable providers of healthcare because they contribute so significantly to the health economy. Last year, hospices in Scotland spent over £55 million on caring for patients, their carers and families.

Hospice care goes far beyond inpatient beds – 80 per cent of the people cared for use community or home-based support (see Figure 1).
This is still not enough. Over the next five years more than 270,000 people will die in Scotland.² Most of these deaths will follow a period of chronic illness, yet it is estimated that some 53,000 people – almost 20 per cent of all deaths in Scotland – will not receive the care they need.³

The Scottish Government’s commitments in the Programme for Government and the Strategic Framework for Action on Palliative and End of Life Care are positive steps toward closing the gaps. Hospices will have a vital role to play in helping to deliver the aims for all people who need palliative and end of life care.

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**Figure 1: Proportions of people seen in the four main service types (adult charitable hospices)**

- **Bedded/inpatient services**: 20%
- **Community/hospice at home services**: 53%
- **Day/outpatient services**: 16%
- **Bereavement care**: 12%
Hospice care in Scotland in 2014-15:
Key statistics

- 20,600 people were directly helped by charitable hospices
- 240 inpatient hospice beds
- 30% of people returned home after a spell of care in a hospice bed
- 4,000 people were admitted to a hospice bed
- 9,500 bereavement support sessions were held
- 500 children and young people were supported by bereavement care
- 2,700 adults were supported by bereavement care
- 85% of hospices provide 24/7 telephone advice to the public and clinicians
- 92% of hospices provide education and training to GPs, hospitals, community teams, care homes, medical and nursing students, and more
All figures refer to 2014-15, all figures have been rounded, and include estimates by hospices where exact data were not available.

* Number of new people seen in the period 2014-15

** estimated

** Hospice UK (2016) Hospice Accounts: Analysis of the accounts of UK independent voluntary hospices for the year ended 31 March 2015

11,000 people were seen by community care and hospice at home*

7,700 complementary therapy sessions given, from massage to meditation

2,400 people were seen in day hospice and outpatient care*

37,000 contacts with people in day hospice and outpatient care

300,000 hours were given by volunteers to charitable hospices**

£55 million was spent by charitable hospices on services**

£3.7 million needs to be fundraised every month by charitable hospices in Scotland

39% the average statutory contribution to the costs of running adult hospices**

14% the average statutory contribution to the costs of running children’s hospices**
Anyone with a condition that is terminal or life shortening could benefit from hospice care and support. In 2015, 57,600 people died in Scotland; of these, experts estimate that 43,500 may have needed expert care at the end of life. People with a cancer diagnosis are currently overrepresented in hospice care referrals. Charitable hospices estimated that vast majority of the referrals they received in 2014-15 were for people with cancer. Hospices estimated that referrals for people with respiratory disease and heart failure made up only three per cent and two per cent respectively.

**Key facts:**
- In 2014 cancer caused 29 per cent of deaths in Scotland, but was the primary diagnosis in 87 per cent of referrals to hospice care.
- Cancer, coronary heart disease, stroke and respiratory disease, accounted for 62 per cent of deaths (some 35,700 people). The majority of these people could potentially benefit from hospice care.

**Figure 2: Comparison of indicators and estimates of need for palliative care in Scotland**

Too many people who would benefit from hospice care are not being identified, assessed or referred. In his report for the Scottish Parliament’s Health and Sport Committee, Professor David Clark estimates that there are 10,600 people a year in Scotland who would benefit from palliative care but do not currently receive it. We know that people with a non-cancer diagnosis tend to be referred to hospice care in fewer numbers and later than those with a cancer diagnosis. Inequality of access due to diagnosis is a critical issue that must be addressed as a matter of urgency.
Hospice care in Scotland

Around a quarter of people who die in Scotland currently benefit from hospice care.

Figure 3: Estimated numbers of people cared for in the four main service types (adult hospice care)

Community and hospice at home

People do not have to go to a hospice building to receive hospice care. Hospices have worked hard to find ways to enable more people to stay at home for longer periods of time, and to die at home. One study found that people receiving Marie Curie’s at-home nursing care were actually twice as likely to die at home than those who did not receive such care.\(^8\)

In Scotland, almost three times as many people are supported in their own home than are cared for in hospice inpatient beds. ‘Hospice at Home’ services allow people to receive hospice care in their own home. This helps to prevent people being admitted to hospital unnecessarily and can also provide families and carers with a break. In providing such care, hospices work closely with other health professionals such as GPs and community nurses.
People who receive care at home are more likely to die at home. Furthermore, evidence suggests that being supported to die at home gives people better experiences, more peace and no more pain than people dying in hospital.

Key facts:
- 85 per cent of Scotland’s hospices offer community or hospice at home care.
- 11,000 people were seen by community or hospice at home services.
- 66,500 community and home visits made, including 10,000 community or home visits for babies, children or young people.

“Before David died my two adult children came home and were most anxious that enough was enough and Dad had to be taken into hospital or hospice. That wasn’t his wish, that wasn’t the way he wanted to end his life. He wanted to be at home and so the hospice at home team made that possible for us, but also helped me explain to the children that we could all manage this together as a team […] and we were all engaged in this effort to make it as good a death as possible.” – Mrs E.G

Figure 4: Numbers of bed days, home/community visits, contacts and appointments across the main types of hospice services
Hospice inpatient beds

Some people have complex symptoms that cannot be controlled at home, or may not have people around them who can support them at home. In these instances, care in an inpatient hospice bed may be appropriate.

Hospice inpatient beds help people to manage pain and other symptoms, and provide respite for carers. For around 30 per cent of people who are admitted, a period in a hospice inpatient bed is brief and they return home.

Key facts:
- Hospices provide 240 beds across 17 inpatient units.
- 4,000 people were admitted to an inpatient service in the year ending March 2015.
- The average stay in an inpatient setting was 19 days.
- 30 per cent of people return home after a stay in an inpatient hospice bed.
- Hospices provided 76,000 nights of care in 2014-15.

Day hospice and outpatient services

Hospices provide a range of services that allow people to get the care and support they need without being admitted to an inpatient bed. This includes medical and nursing care, counselling, art and music therapy, massage, meditation, complementary therapies such as aromatherapy, as well as hairdressing in on-site salons.

All hospices in Scotland offer this sort of care, so that people can attend a comfortable environment to access a range of clinical services and complementary therapies. Day hospice also offer opportunities to socialise and make new friends, and to receive non-clinical support, such as welfare advice.

A lady who was attending day hospice met with the service’s psychologist. She was in the advanced stages of terminal illness and had almost completely lost her appetite. Her husband prepared many meals for her, and became distressed when she did not eat. Both experienced her rejection of food as rejection of the husband. This placed a strain on their marriage.

With the psychologist, the couple were able to explore this tension, talk openly about this phase of her illness, and look at other ways the husband could show his love and affection. This meant that the couple were able to care for one another and make the most of the time they had left.

Being able to access hospice care through day and outpatient services means people can get care, advice, support and company in a way that works for them. Day and outpatient services in Scotland’s hospices cover a wide range of services attending to people’s physical, psychological, emotional and social needs. All hospices offer medical consultations at day and outpatient settings but they also offer wider services.

Key facts:
- All hospices in Scotland provide some form of day hospice/outpatient care.
- 2,400 people were seen in day hospice/outpatient services.
- 37,000 contacts with people in day hospice/outpatient services.
Bereavement care

Over 200,000 adults and children are affected by the death of a loved one every year in Scotland. Eleven children are bereaved of a parent every day.¹¹

Bereavement can lead to a number of poor outcomes across health, income and employment.¹² Hospices offer support, both before and after a death, to help people manage what can be a painful and isolating experience. Such support may be through formal engagement with a professional therapist, group sessions, or more general social support and information.

Key facts:
- 2,700 adults used hospice bereavement support.
- 500 children and young people used hospice bereavement support.
- 9,500 bereavement support sessions were held.
- 93 per cent of Scottish hospices offer bereavement services.
- 64 per cent of hospices accept referrals for bereavement support from outside their own service (that is, the person’s loved one does not need to have been cared for directly by the hospice).
Supporting care in other settings

Despite our best efforts, not everyone will have the chance to decide where they will be when they die. As a result, the majority of hospices in Scotland also provide support to people, clinicians and staff in other care settings such as hospitals, care homes and more. Telephone based support, for people and clinicians, is extremely important. Being able to call a hospice for advice on medications, pain relief, breathlessness and anything else can mean the difference between staying at home or an unnecessary and uncomfortable trip to Accident and Emergency.

Key facts:

• 93 per cent of Scottish hospices provide telephone advice to people and to clinicians, and the majority deliver this on a 24/7 basis.

• Hospices provide support to a wide number of community settings, such as care homes, homeless hostels, prisons, and accommodation based support for people with learning disabilities.

Figure 6: Proportion of Scottish hospices supporting care in other settings/channels

One of the big challenges in reaching everyone who needs hospice care is Scotland’s geography. To address this one hospice is implementing Project ECHO (Extension for Community Healthcare Outcomes). Project ECHO is a ‘hub-and-spoke’ knowledge sharing network model, initially developed New Mexico to ensure people with Hepatitis C across a large geographic area received the treatment they needed despite the lack of local specialists.

In Scotland, Project ECHO will take hospice care out to the places people live, building capacity and knowledge in local health and social care practitioners, thus enabling more people to benefit from specialist care. Delivered over the internet, a consultant will lead collaborative, problem solving sessions for GPs, nurses and other practitioners to support their work with people with terminal and life shortening conditions in their communities.
Hospice care for babies, children and young people

The Children’s Hospice Association Scotland (CHAS) is the only charity in Scotland that offers care exclusively for babies, children and young people with life-shortening conditions. Around 20 per cent of hospices in Scotland support young people from 14 years of age.

Similar to adult hospices, children’s hospice care offers clinical, therapeutic and emotional care and support for the whole family. There are two inpatient children’s hospices in Scotland, and support for people in their own homes through the hospice at home service. As more and more young people with complex needs are able to live well for much longer there is also a need to help young people transition from children’s hospice to adult hospice care.

In 2014-15 there were around 400 children and young people referred to children’s hospice care. There are approximately 200 deaths per year among children and young people with life-shortening conditions and around one-third of these children are cared for directly by children’s hospice care.13

Key facts:
• 10,000 bed nights for families provided in the two children’s hospices in 2014-15.
• 1,000 visits to children and families in their own homes.14

While the number of children who need hospice care and die each year is relatively small compared to adults, their needs and the needs of their families and carers can be extraordinarily complex over several years. Children’s hospice care also nurtures children through their developmental milestones, and supports experiencing the world through play and social interaction with their peers.

Seventy-three per cent of deaths among babies, children and young people happen in hospital.15 By providing support for clinicians in acute settings and employing three children’s nurses to work in hospital and community settings, CHAS enables more children and young people to access children’s hospice care. CHAS is also working with health professionals and families to support home transfer from hospital to allow families to take their children home, even in the very last stages of their illness.

Zahra was born prematurely and was diagnosed with a life-threatening condition shortly after birth. Zahra’s parents and the neonatal team agreed she had palliative care needs and a referral was made to hospice care. The team, made up of CHAS and neonatal staff working together, cared for Zahra and her family. This care included supporting conversations about end of life choices, and life beyond.

Hospice care enabled Zahra’s family to take her home to die when it was clear neonatal intensive care was no longer in her best interests. Collaborative working provided the opportunity for enhanced end of life care and support. Zahra was brought home to spend the last hours of her short life in the loving care of her family, in her own home for the first and last time.

“When we knew our baby was going to die it was important she had a ‘good death’. Taking her home allowed this to happen.” – Zahra’s mum
Research and education

Research and education have been fundamental pillars of the hospice movement since its inception almost 50 years ago. Hospices need an evidence base for the care and treatment they provide, as well as testing and improving the interventions that improve people’s outcomes. This is often research that would not happen anywhere else in the health system.

A commitment to research drives a culture of learning, which in turn is disseminated through wide-ranging educational work. Hospices deliver education and training to health and care professionals working across the care system.

Key facts:

- 92 per cent of hospices in Scotland have an education or practice development function.
- 92 per cent provide education in hospice care to their staff.
- 77 per cent provide education to external staff (including staff in acute and community hospitals, care homes, local councils, other third sector organisations, people in the community, and healthcare students).

Volunteering

Volunteers are integral to hospice care. Hospices rely on volunteers to deliver the quality of care they do.

Volunteers undertake administrative tasks, driving roles, running receptions and cafes, being on the inpatient unit, running classes, to name a few. What can seem like a small task, like changing the flowers in a hospice room, providing a haircut, or helping someone attend day hospice, can mean a lot.

There is no doubt that volunteers save hospices and the NHS enormous sums of money. However, it’s not just about saving money, volunteers make a real difference to people who use hospice care by offering friendship, ‘ordinary’ interactions and the sharing of diverse skills and experiences.

Key facts:

- Thousands of volunteers delivered an estimated 318,000 hours of voluntary work in 2014-15.
- More than 72,000 hours were spent caring and supporting people using hospice services directly.
- Over 246,000 hours were spent raising funds, from one-off engagements to regular commitments in hospice charity shops.

Isolation amongst older people is a growing social problem. Many older people living with a terminal diagnosis, or caring for someone with a terminal or life-shortening condition, can find themselves particularly isolated. In response to the Scottish Government’s ‘Reshaping Care for Older People’ initiative three Scottish hospices joined together to deliver community palliative care support services in older people’s homes, such as Community Nurse Specialist care, complementary therapy and pairing with a volunteer befriender – someone who visits, talks, listens and promotes confidence and independence. The project is improving the lives of many older people by improving confidence, mood and wellbeing among people at the end of life, as well as reducing stress and isolation among carers.
Funding of hospice care in Scotland

Hospice care is provided at no charge to the people who use it. Adult and children’s hospices in Scotland spend a combined £55 million a year on providing care, and the majority of this is generously provided by local people and local businesses. Despite a commitment from the Scottish Government to meet 50 per cent of agreed costs in adult hospices, statutory funding currently provides for 39 per cent of the cost of delivering care. Children’s hospices are supported at a much lower level, receiving 14 per cent of the cost of providing care from the NHS. As such, hospices are major funders and commissioners of palliative care.

Key facts:

- Hospices in Scotland spend a combined £55 million per annum on providing care.
- Scottish hospices need to fundraise £3.7 million every month.16
- The statutory contribution to the costs of running adult hospices is 39 per cent; and 14 per cent for children’s hospices.

Over the coming year the commissioning of hospice care will move from Health Boards to the new Health and Social Care Partnerships (H&SCPs). The current commitment to fund 50 per cent of agreed costs is between the Scottish Government and Health Boards. It is not known if this commitment will be extended to H&SCPs.
Opportunities

Hospice care in Scotland is at a pivotal moment driven by external influences. On the verge of significant social and demographic change, and with major Government programmes and structural changes underway, there is an extraordinary opportunity to build the right hospice care for the next 50 years. To achieve this vision we propose:

A community driven response is vital

Hospices have their roots in the communities that they serve, and are ideally placed to help communities meet the challenges of care at the end of life. Hospices support communities to do much more in caring for people at the end of life, from helping family and loved ones, to co-ordinating community-based volunteer support.

Death and dying should be included in the new public health strategy

It is imperative that the Scottish Government includes death and dying in the new public health strategy. Encouraging more open and honest conversations about dying, death and bereavement, and tackling society’s taboos should be included in the strategy. The strategy should also support clinicians to understand more about the needs of people with terminal and life-shortening conditions and to make better use of the network of care available through hospices.

People need a seamless health/social care experience

People and families living with terminal and life-shortening conditions need help from multiple sources – across social and medical care – and across statutory, third sector and private providers. Social care that cannot be put in place quickly enough can leave people stranded in hospital or hospice inpatient care when they wish to return home. Lack of appropriate community care can lead to unnecessary hospital admissions. Health and Social Care Partnerships need to look at the myriad of services people need and ensure they are commissioned and delivered in a joined-up way.

Where Integration Joint Boards have Managed Clinical/Care Networks (MCNs) in place for palliative care, hospices need a reliable and consistent named link role. Every MCN should have a consistent link to develop relationships with hospices to improve the standards of care for people with terminal and life-shortening conditions.

Hospices need to be recognised as community assets

Hospices need to be seen as a community assets that provide much more than hospice beds. Health and Social Care Partnerships are required to map out the needs of their populations and localities, and part of this work will be identifying community assets to meet the needs of those populations. H&SCPs should recognise the full range of community services that hospices provide, including specialist community nurses, day therapy work, carer and support groups, and bereavement work, as well as community nursing.

We need better intelligence

Across the health and care system, we need better intelligence about death and dying based on robust data and analysis. The Scottish Government’s commitment in the Strategic Framework for Action to improving the collection, analysis, interpretation and
dissemination of data and evidence relating to palliative and end of life care is an important step. Hospices and people using their services should be involved in this work to ensure the right data is in scope.

Better intelligence will also support reporting against the outcome measures set by Health and Social Care Partnerships (H&SCPs). To achieve these aims, hospices will need additional resource from the Scottish Government and/or Health and Social Care Partnerships.

Reliable funding is essential to planning and delivery of sustainable, long term services that meet the needs of local communities

The Scottish Government is currently undertaking a review of hospice funding to ensure parity between children’s hospices and adult hospices. This review is an opportunity for the Government to restate its commitment to 50 per cent funding of hospice care to all those responsible for commissioning hospice services.

“What if our aim is not giving up but making the best day possible for you, however you might define it under the circumstances ... would that be worth hoping for? Worth fighting for?”

Atul Gawande, Reith Lecture, Edinburgh 9 Dec 2014

Methodology

Hospice UK undertook a quantitative survey of Scottish Hospices February–June 2016. Hospices were provided with a questionnaire in advance of a telephone interview to record their responses. This report is based on the aggregate findings of that survey. The survey is available on request to Hospice UK.

A key challenge in understanding the data is the lack of individual identifiers of people using services, thus we are unable to 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, such as hospice at home and inpatient care. Therefore, the calculation of the total number of people receiving direct care from Scottish hospices may include some double counting.

The calculation of bed days in adult hospices is average number of days in inpatient unit multiplied by number of admissions.

In order to maximise confidentiality and for ease of communication figures have been rounded.
1. Charitable hospices are organisations providing hospice care (in any setting) that are not for profit, independent of the NHS and rely predominantly on fundraising in their communities to be able to deliver care. Most hospice care in the UK is provided by charitable hospices. The NHS also provides hospice and palliative care. GPs, district nurses, paid carers and health and social care staff in hospitals and care homes can provide some palliative care. However, they will use a hospice or palliative care team when more specialist support is needed.

2. Calculated from ISD Scotland data see http://www.isdscotland.org/Health-Topics/Deaths/


4. Murtagh, F., et al, (2014) ‘How many people need palliative care? A study developing and comparing methods for population-based estimates’ Palliative Medicine, Vol 28(1) 49–58. The paper states that between 69 - 82 per cent of all deaths in high-income countries would benefit from palliative care. For ease, we have used the midpoint (75.5 per cent) to broadly estimate how many people might benefit from palliative care in Scotland each year.


15. Fraser, op cit.

16. This figure is based on the amount Scottish hospices need to bring in to cover their expenditure, defined here as total spend less government funding and investment income.


References