



Impact report 2018–2019

Messages from our Chief Executive and Chair



This year has been one of the most rewarding and challenging I have faced since joining Hospice UK.

With growing demand and shrinking resources, hospice and end of life care is at a crossroads. It is vital we change and adapt in order to make sure that care is there for everyone who needs it in the future. But hospices cannot do this alone.

This is why now, more than ever, our work as the national charity for hospice and palliative care is so important. From funding innovative new hospice projects and providing vital training, to campaigning for better access to hospice care and raising awareness of the challenges, we have helped hospices take the vital care they provide out to people where and when they need it.

A big part of this has been the way we have used technology to make sure more people can access hospice quality care. Now in its third year, our Project ECHO is helping to ensure more care providers, like care homes and hospitals, get the support they need to provide good end of life care.

We have also been working hard to support the communities in which hospices are rooted – a key commitment in our five-year strategy. We launched a number of new projects, one of which is our Compassionate Employers programme, which will help people affected by end of life issues be better supported in their workplaces.

I have visited many hospices throughout this year, and it is humbling how dedicated the

staff are to delivering a haven of care for their patients and families. We are so fortunate to have this magnificent service available for free, but we cannot take it for granted.

That is why I would like to say a huge thank you to everyone who has supported Hospice UK and hospice care this year. That includes all our grant partners, the many individuals who have done the hard yards in taking on challenge events, the London Fundraising Committee for putting on so many great fundraising events, and our corporate partners.

There is much to do, but as you will see in this report, together we are making a difference in getting the best possible end of life care for everyone who needs it. I hope this inspires you to continue the journey with us to do even more into the future.

Tracey Bleakley
Chief Executive
Hospice UK

I am immensely proud to be the Chair of Hospice UK, and of what we have achieved over the past year.



At the end of a person's life, we only have one chance to get it right. The amazing work of our dedicated staff, members, partners and supporters are helping to make sure we're getting it right for more people. But there is still so much to do, and with your support we will continue to work tirelessly to open up hospice care so that everyone who needs it, gets it.

Robert Peston
Chair
Hospice UK

Why we are here

Hospice UK is the national charity for hospice and palliative care. 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. No one should die in avoidable pain or suffering.

Our mission is to transform the way society cares for the dying and those around them. We empower individuals and communities to embrace hospice care, and extend its breadth and reach to improve everyone's experience of death, dying and bereavement.

In all that we do, we focus on the people in need of palliative and end of life care, people like Xanthe, Naomi and Isaiah and their families, who all deserve the best possible care and support where and when they need it.

That is why we listen to and consult with people who have personal experience of end of life care when developing our programmes of work. We do this through our People in Partnership

Forum, which includes people with life-limiting conditions, people who are bereaved, carers and former carers.

In order to achieve the best possible care for everyone, the following key strategic priorities underpin our work:

- Extend our reach and enable hospice quality care to be delivered in any setting.
- Tackle inequality and widen access to hospice care.
- Work with communities to build capacity and resilience to care for those at the end of life.
- Empower a strong, dynamic and responsive hospice sector.

Personal stories from hospices

Xanthe

"I think what was really helpful about the Hospice at Home team was how they cared for us as a whole family.

"They cared about how I was doing. They cared about how the children were doing too."

"Having special time together with Sam in those last few weeks as a wife, but also as a Mum – and for him being able to be a Dad – was really important. Hospice at Home allowed us to be a family together, the four of us, at the end."

Arthur Rank Hospice



Naomi and Isaiah

"Isaiah loves coming to the hospice. It means he can have dedicated one-to-one attention with someone other than me, and can take part in lots of different therapies and activities which help him relax."

"It's a chance to get some sleep, to talk to other parents who understand how I'm feeling, and to be around people who listen, while knowing that Isaiah is having loads of fun and receiving amazing care."

The Donna Louise Children's and Young People's Hospice



Hospice quality care everywhere

Over 600,000 people are dying in the UK each year – and one in four are not accessing the palliative care they need at the end of life. Hospices alone cannot meet the growing demands for end of life care. It is vital we help to increase capacity and quality of care beyond hospices and build strong sustainable partnerships between hospices and others such as GPs, hospitals and care homes.

Using technology to increase capacity and quality of care

Our **Project ECHO** (Extension for Community Healthcare Outcomes) uses video-conferencing technology to develop communities that enable healthcare professionals to learn from and support each other to build their expertise and increase reach. This ensures better care for patients and their families whether they are in hospital, at home or in a care home.

Already in its first two and a half years, we have trained 24 organisations, including hospices and NHS trusts, to use the ECHO technology. These organisations have gone on to develop 39 communities in areas including dementia,

GP support, community nursing and cardiology, which are all helping more people access better end of life care and faster.

Feedback from care home staff shows the difference ECHO is having for their patients:

“Pain management care plans have been revised and training with staff about recognising signs of pain is being highlighted across the organisation. Understanding this better is helping with supporting distressed residents.”

Care home worker

Helping improve end of life care in hospitals

A large percentage of people die in hospital every year, and many more receive care in hospitals in their final months of life. Our 'Fresh eyes' programme, undertaken with our People in Partnership Forum, aimed to help hospitals see things from a patient and family's perspective.

Expert teams, including people with personal experience of end of life care, visited 12 hospitals to help them consider the patient, family and/or carers' experiences of the care they provide. The team then fed back on areas where the hospitals could improve in order to provide better quality, compassionate care.

We were delighted that our 'Fresh eyes' programme **won the Environment of Care award** at the Patient Experience Network National Awards.

"As staff, it helped us to understand how things seem for the people using our services. The outputs gave us tangible changes to implement and also suggestions that provided us with the opportunity for rich discussions about subjects we may never have discussed."

Hospital bereavement staff member





Funding innovative new hospice projects

Our grant programmes are a key way we help more people access the care they need. For example, thanks to a grant from our Rank Foundation programme Rennie Grove Hospice Care in Hertfordshire has set up a Horticultural Therapy Project. The project enables patients of all ages to get together to plant seeds, cuttings and bulbs, pot up containers and nurture plants and flowers – all in a brand new specially-adapted greenhouse complete with wheelchair access and low-level benches.

“Horticultural workshops enhance wellbeing, improve mobility, assist recovery from treatment and operations and enable social support. The project is a significant addition to the range of nursing, complementary therapies and support services we already provide at Grove House, and will make a practical difference to the lives of patients and their families.”

*Julie Hill, Senior Occupational Therapist,
Rennie Grove Hospice Care*

A grant from the Masonic Charitable Foundation to St Christopher's Hospice in South London enabled them to set up Bereavement Help Points in community spaces like libraries, so they could take their bereavement information, support and advice out to the communities they serve.

"The Help Point has become one of the essential services at the library hub. Bringing the service into the community has opened up a world of support for those people who would not otherwise access the service."

Upper Norwood Library

"I really wanted to let you know how much of a life-saver the Help Point is. I don't know how I would have got through Christmas if it had not been for the lovely ladies that I met on my visit."

Help Point visitor

We awarded
375
grants
totalling
£1.5
million

Tackling inequality and widening access to hospice care

Access to hospice care is currently unequal. More than 335 people every day won't access the expert care that hospices provide. People with dementia, heart and liver failure, lung disease and frailty would benefit from hospice care but are not being referred. Children with life-shortening conditions are now living longer and need support to transition into adult services. Many groups such as certain faith groups, homeless people, prisoners and the traveller community are disadvantaged at the end of life and can't get hospice services.

Tackling inequality

An important piece of work we are doing is helping more Gypsies and Travellers, the LGBT community and people experiencing homelessness to access good, personalised end of life care.

To tackle the inequality these communities experience, we have partnered with several organisations (as part of the Health and Wellbeing Alliance), including Homeless Link, The National LGB&T Partnership, and Friends, Families and Travellers, to produce guidance that healthcare professionals can use to improve the care they offer. With this guidance,

we are making a big difference to potentially thousands of vulnerable people by giving care providers the tools to meet their needs.

Helping people find information

This year we helped over **30,000 people** access the support they need when they needed it, through our online information resources, including our hospice finder, or by calling our team for help.

"Thank goodness there are organisations such as yours to help with support during some of the darkest periods of life."

Caller to Hospice UK

Open up hospice care

Running for the whole of March, our **Open Up Hospice Care** campaign mobilised hospices and supporters to highlight the need for more people to be able to benefit from the vital services they offer.

Along with hospices, we shared stories of amazing care, raising awareness of what is available but also the need for more funding and support to enable more people to access it.

These stories reached **millions of people** across the UK through our website, social media and online film to raise awareness of what hospice care can offer them and what is needed to make sure more people can access it at the most vulnerable time of their lives.

Over **£60,000** was raised and will go towards our vital work to improve access to good quality end of life care for more people.





Working with government to influence policy

Key to widening access to end of life care is influencing government policy. We give a voice to people in need of and providing end of life care, and our policy and advocacy work on improving access to care has picked up pace this year.

Last year, we helped the Cross Party Group on Hospices and Palliative Care in Wales to report on inequalities in access to care. The recommendations in the report are now being put into practice, and are a step forward in making sure more people in Wales get the care they need.

In England, we supported the All Party Parliamentary Group on Hospice and End of Life Care. This year we facilitated two oral evidence sessions on improving access to care, attended by parliamentarians from across the political parties, as well as hospice leaders and policy professionals from other charities and organisations. This enables us to influence thinking at a level where major, large scale change can happen.

“Thanks to significant funding from Hospice UK, we are breaking down taboos around death and dying and empowering local people in the rural town of Kingsbridge, Devon to put compassion at the heart of the community so that no-one feels left behind.

“In a location like this, where it can be more difficult for people to access all kinds of services, including end of life care, local people, voluntary groups and businesses are coming together to show kindness and give practical support to terminally ill people and those caring for them who would otherwise risk isolation and loneliness.”

Steve Statham, CEO, St Luke's Hospice Plymouth

Building capacity and resilience with communities

Through a range of projects, we are helping to empower communities to be resilient, to talk about their wishes, and be able to help care for people at the end of life.

Community Volunteering Hub

This new online hub enables hospices to access the expertise and willingness of volunteers within their communities. This is helping to reduce the isolation experienced by people at the end of life through better access to hospice services and in turn giving volunteers a greater sense of purpose, and better health and wellbeing.

"I was matched with a very elderly lady who was previously unaware of the support offered by the hospice and is very grateful for being referred to this project. I am retired. I live alone and can get lonely too. We both look forward to our weekly meetings."

Hospice volunteer

Building compassionate employers

One in three people of working age in the UK suffer from a long-term condition.

Over a million people are caring for a family member with a terminal or life-limiting illness. These people will often encounter difficulties in their working life, which is why we have developed our Compassionate Employers programme.

The programme will help employers to create a more compassionate workplace, and give them the practical tools they need to support their employees who are affected by terminal illness, caring and bereavement.



Community Development Toolkit

This toolkit enables care providers to listen, discover and learn from their communities. This will have an impact on how communities support people who may be lonely, bereft, at the end of life or those caring for someone who has a life-limiting illness.

Talking about dying and grief

A lack of openness around death can affect the quality and range of support and care people access as well as personal end of life choices. Our Dying Matters campaign aims to help people talk more openly about dying, death and bereavement, and encourage everyone to make plans for their end of life.

**Dying
Matters**

*'Let's talk
about it'*

Every year in May, we hold the Dying Matters Awareness Week. Over **400 events** took place during the campaign week, and **800,000 people** saw our messages on social media, all of which helps to break down the barriers around talking about death and bereavement.



Empower a strong, dynamic and responsive hospice sector

We recognise that in order for people to be able to get the best possible care at the end of their lives, we need to give strong leadership and support to those providing the care. There are many ways we do this.

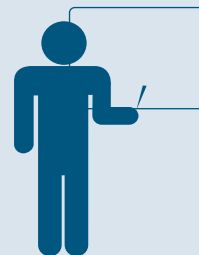
Enhancing expertise

We run a governance programme, which supports hospice trustees and boards to be leaders in providing high-quality end of life care. We offer a range of resources and training events, and this year we published a new guide to being a hospice trustee and ran our first hospice trustees conference.

Sustaining hospice care

Communities are committed to supporting their local hospice and help them to raise over £1.4 billion each year. Nationally, our programmes of training, corporate partnerships, campaigns and other resources and guidance aim to help hospices to continue to sustain those services.

1,773
people attended
**18 learning
events**



Through this work, we are able to help care providers with the skills, knowledge and support they need to make a difference to the care people receive.

Celebrating and promoting hospice care

Hospice Care Week brings hospices together to showcase the amazing care and support they offer, helps to dispel myths, and provide an opportunity to raise much needed funds.

Our 2018 campaign focussed on what people love about their local hospice, reaching **millions of people** through social media and articles in the media. We also took over King's Cross Station in London on one of the days, which enabled us to raise the profile of hospice care with the thousands of commuters who passed through the station.



hospice care week
8-14 October 2018





Advocating for hospices and the people they care for

This year, we secured **£25 million** extra investment for hospice and palliative care services in England from the government, and a commitment to review the funding of palliative and end of life care. This highlights the influence we can have to help make sure more funding is available so people receive the care they need.

We also successfully prevented hospices facing an extra **£100 million** of new costs over three years as an unintended result of the increase in employer contributions to the NHS pension scheme. This is money that can be redirected to patient care.

“It isn’t just the financial help from Hospice UK that makes a difference. The national platform the charity provides through its campaigns raises awareness of the challenges our sector faces, helps us recruit and retain staff, and highlights the ongoing need for government investment in our services.”

Hospice CEO

Thank you to all our partners and supporters

Grants

We would like to thank our grants programme partners, including:

- Albert Hunt Trust
- Masonic Charitable Foundation
- National Lottery Community Fund
- Rank Foundation
- St James's Place Charitable Foundation

Plus all the many other trusts and foundations for their valued support throughout the year.

Events

We would also like to thank the London Fundraising Committee for supporting several important fundraising events in 2018–2019, including our Christmas Carol Service, 35th Anniversary Gala Dinner, and Fashion Lunch.

We are grateful to the hundreds of people who took part in challenge events to raise vital money to support our work.

Corporate partners

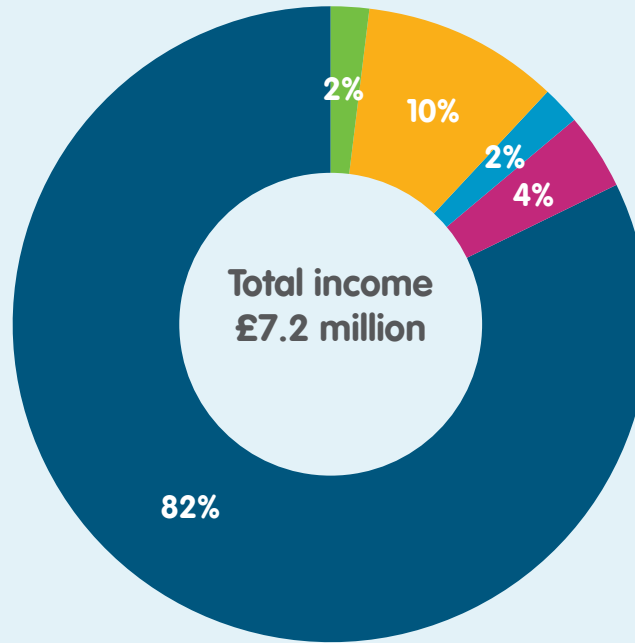
Our corporate partners have also made a huge contribution this year. Thank you to:

- AB InBev
- Ageas
- Amazon Smile
- Barclays
- CYBG
- Co-operative Banking Group
- Deloitte
- Joules
- London Business Forum
- New Look
- The National Garden Scheme
- Towergate Insurance
- UM Group



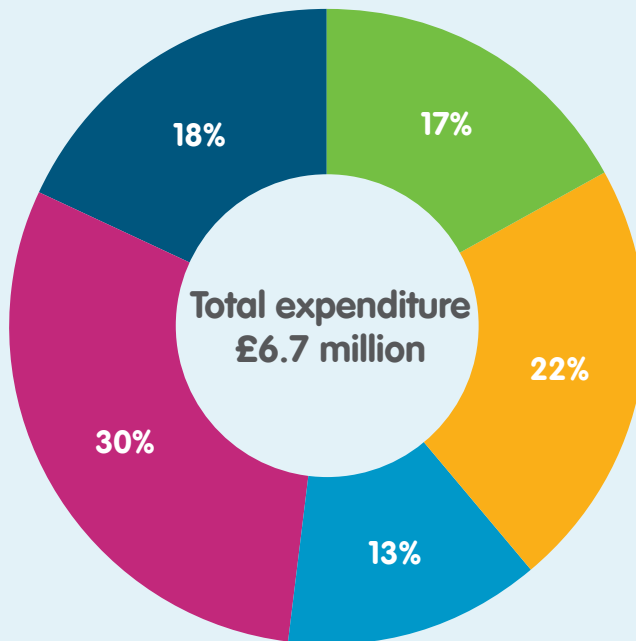
Our income and expenditure

Income



- Investment income
- Income from charitable activities
- Income from other trading activities
- Membership fee income
- Fundraising income

Expenditure



- Extending our reach
- Tackling inequality
- Working with communities
- Empowering a strong hospice sector
- Costs of raising funds

A photograph of a smiling man with a grey beard and a young boy in a doorway, overlaid with a blue tint. The man is wearing a light-colored shirt and holding a cane. The boy is seen from the back, looking towards the man.

www.hospiceuk.org 020 7520 8200

 **@hospiceuk**  **/hospiceuk**

Hospice UK, Hospice House, 34 – 44 Britannia Street, London WC1X 9JG

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