



# Hospice UK

## Impact Report 2019 – 2020







## Introduction from Tracey Bleakley CEO of Hospice UK

**This past year has been exciting in many ways, but it has also been one of the most challenging. The COVID-19 pandemic has posed many hurdles for hospices and for people facing a terminal illness or the end of their lives, and it has created a lot of change in the way we work and view end of life care.**

Our ongoing theme through March 2019 – April 2020 has been 'Evolution and Revolution'. We've looked at the challenges facing those dying and their families today and considered what we can do to meet immediate needs but also to look longer term at the change necessary in end of life care.

This year's Hospice Care Week's theme of *This is What it Takes* is a powerful reminder of just what goes into hospice care, championing everyone involved from the doctors, nurses and physiotherapists to the gardeners and chefs who provide wellbeing spaces and nutritious food.

Our work is varied. This year our partnership with the National Garden Scheme has continued, enabling so many people to enjoy gardens around the UK and raise funds for health charities. We have provided grants to hospices to open up hospice care to communities who traditionally haven't accessed palliative care, and we have helped people find the support they need through our "Find a Hospice" service on our website.

Dying Matters saw over 400 events take place in 2019. It has seen a revamp of resources and a new social media campaign, I Remember, which celebrates the lives of loved ones who have died.

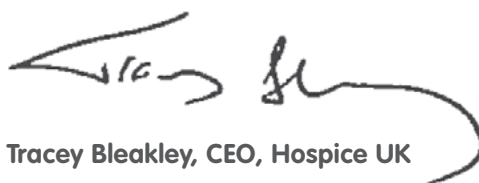
Remembrance has become ever more pertinent since COVID-19 as people adjust to new ways of living and coping with unexpected death.



We have established support lines for frontline workers who may be experiencing mental health issues, ensured hospices got PPE and we are delighted to have been able to successfully secure funding for hospices at this difficult time.

In 2019, Hospice UK staff chose the following Hospice UK values: Collaboration, Compassion, Innovative, Inclusive and Knowledgeable. Looking at our achievements over the past year, I feel that we have upheld these values and I hope you will see this reflected in our accomplishments.

I would like to thank everyone who has supported Hospice UK. Individuals, trusts, grant partners and corporate partners; your support really makes a difference.



Tracey Bleakley, CEO, Hospice UK



## Who We Are

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.

**Hospice UK has four strategic goals to:**



**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**



# Our COVID-19 response

2020 is seeing one of the greatest health challenges facing our country in living memory. Hospice UK has been at the forefront of the response since the start, working collaboratively to help those suffering and supporting those who are caring.

*"At the beginning of the pandemic I had a conversation with my husband as he was worried about me, but there was no question that I wouldn't work. I had a duty of care to my patients, our staff and volunteers, and I needed to do all I could."* Dr Sam Edward, Medical Director at North London Hospice

*"I know that by doing my job, I'm adding to patients' safety, comfort and wellbeing. I think it's the fact that we're all working together to make a real difference that explains the lovely atmosphere here at ellenor. It's a place that's about people, putting them and their needs first, and I'm very happy to be a part of that."*

Michelle Aldous, housekeeper, ellenor

*"Hospice UK is delighted that the Government is providing £200 million of funding per quarter to hospices to help support the NHS and respond to the COVID-19 emergency. This unprecedented funding recognises the vital role that hospices play in supporting the NHS in its fight against COVID-19, and means hospices across the country can keep providing beds, specialist clinical care and staffing to relieve pressure on the NHS at this critical moment."* Tracey Bleakley, CEO, Hospice UK

## Securing COVID-19 funding for vital hospice services

**Hospice UK acted quickly, working with the Government to provide extra funding for hospices to respond to the pandemic.**

We were delighted when the Chancellor announced in early April additional funding of up to £200million for the NHS to purchase extra support from hospices in England to deliver additional inpatient capacity and end of life community services.

The Welsh Government announced funding for hospices of up to £6.3m, including £850k to support vital bereavement services.

The Scottish Government stated it would pass on all consequential funding they received from the UK Government, which is anticipated to be up to £19million.

In Northern Ireland, the Department of Finance outlined a support package of £6.75million.

These announcements took commitments for hospice funding across the UK to over £230million.





## Keeping hospice staff safe

**At the start of the COVID-19 crisis, hospices expressed concern over limited supplies of Personal Protective Equipment (PPE) to keep their staff safe.**

In partnership with NHS England and the Department of Health and Social Care, we worked to ensure hospices could get regular supplies of PPE.

Hospice UK co-ordinated setting up 13 regional hospice hubs in England to enable the distribution of vital PPE to local hospices. Each hospice hub undertakes this work voluntarily and distributes over 1 million units of PPE each week.



## Caring for the health and wellbeing of frontline teams

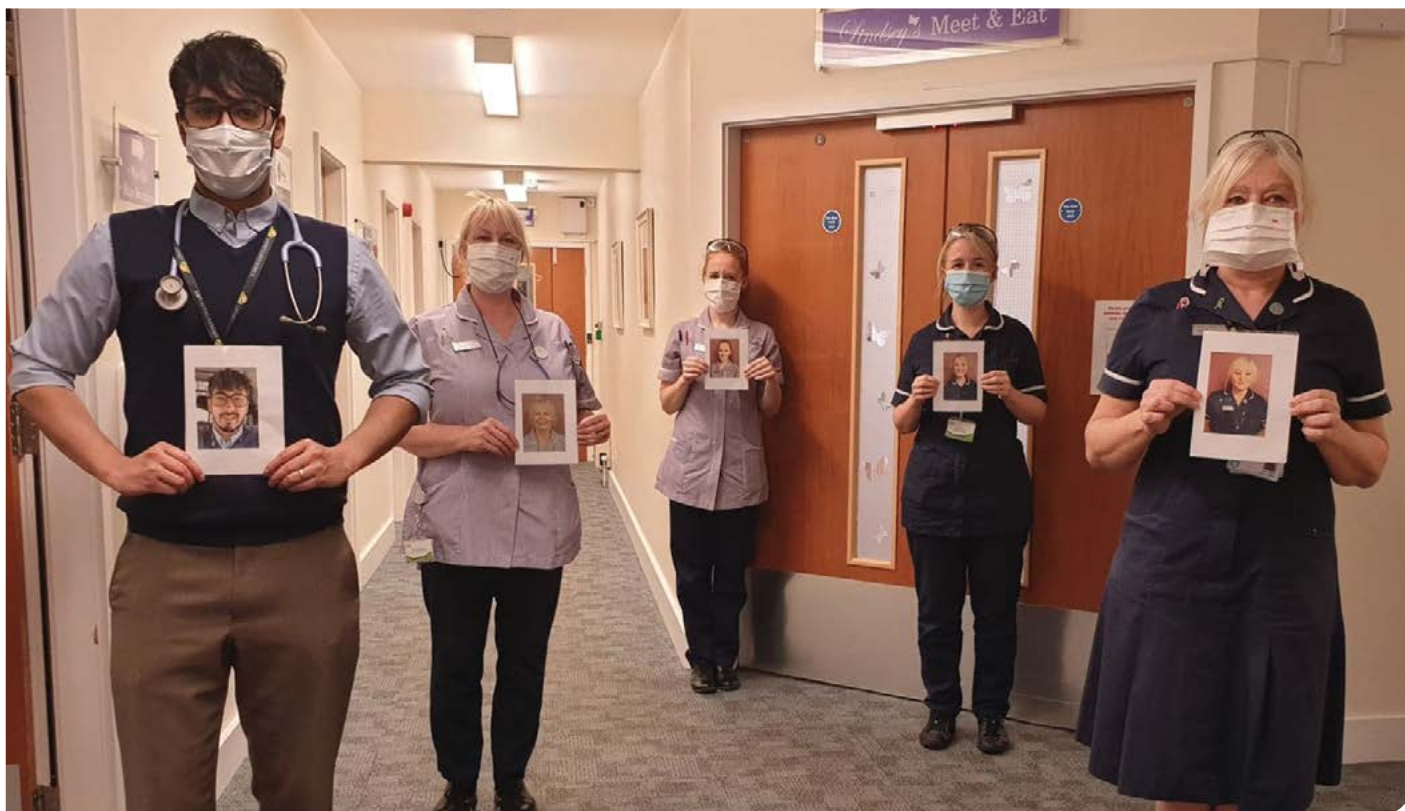
**In partnership with Mind, The Samaritans, Shout and supported by the Royal Foundation, Hospice UK and Dying Matters are proud to be a part of Our Frontline. This is a service providing mental health information and support to key workers on the frontline, including doctors, nurses, care home workers, those in the emergency services and social care.**

The Our Frontline website has been hugely popular with more than 130,000 online page views in the four months following launch in early April 2020.

Hospice UK is also offering a confidential counselling and trauma telephone and email helpline. This service funded by the NHS launched at the beginning of the COVID-19 crisis for NHS staff needing emotional support. Thanks to additional funding from the Royal Foundation the service has expanded to incorporate other health professionals and emergency responders. It is delivered by Just 'B' who are a national team of specialist counsellors located at North Yorkshire Hospice Care, a registered charity in England and Wales (518905) with a family of services also including Herriot Hospice Homecare, Saint Michael's Hospice and Talking Spaces.

*"We couldn't be more grateful to the Duke and Duchess of Cambridge for helping to fund our trauma support at Hospice UK for frontline workers during the COVID-19 pandemic and for being so involved and passionate about making a real difference."*

**Tracey Bleakley, CEO, Hospice UK**



## Crisis support for hospice clinical and business leaders

**Throughout the crisis, the Hospice UK website is regularly updated with guidance and information. In four months, up to 30 pieces of new guidance were produced, many of which had Hospice UK input, to bring clarity and reassurance to healthcare professionals and the public alike.**

Hospice UK expanded their Extension of Community Healthcare Outcomes (ECHO) networks to adapt to a rapidly changing clinical landscape and learn through peer support. Topics ranged from supply of PPE to new approaches in using technology and maintaining human rights.

The fortnightly Business Continuity ECHO focuses on sector leaders coming together to learn from the experiences of others and to think strategically about services moving forward.

It reaches an average of over 200 chief executives, trustees and senior managers across the hospice and end of life sector.

The Clinical ECHO, with an emphasis on the latest clinical evidence and practice guidelines for those managing COVID-19, peaked at more than 300 health leaders and there are now more than 600 people registered to the network. The network has participated in national research studies and enabled rapid response to the challenge of care during COVID. Both networks are continuing through the second surge of COVID.

In addition, we initiated a new network for hospice trustees and another for directors of fundraising including opportunities for them to come together to support and learn from each other's experiences. The monthly meetings for each group are attended by between 50 and 100 participants and highlight the value for these groups that each have very unique roles responsibilities and have been significantly impact by the COVID-19 pandemic.



## Working together

**We have seen an amazing response from all our supporters during this difficult time. Our emergency COVID-19 fundraising campaign raised over £800,000 thanks to the generous support of many people and organisations.**

Joules employees and customers have supported Hospice UK through in-store and online fundraising, and by supplying over 7,000 PPE masks and care packages to their local hospices. We also received a £75,000 donation from The Co-operative Bank.

We would also like to thank the family of Julia and Hans Rausing, and the Catholic Trust for England and Wales amongst many other Trusts and Foundations, for their exceptional support.

Some of the inventive and creative ways our supporters have rallied round to raise vital funds to support our emergency work has been inspiring.



### John Gilbert

91-year old John Gilbert was motivated by Sir Tom Moore's campaign and wanted to say thank you to key workers. He took on his own marathon cycling challenge in aid of Hospice UK and Hospice Biographers.

**John cycled a whopping 175 miles on his indoor pedal exerciser and raising over £4,000!**

### John says:

*"I have visited quite a number of hospices all over the country to visit friends, and have always been impressed by the staff for their understanding and kindness. We all know that the authorities have been under enormous pressure by the onslaught of this pandemic, and help and guidance to hospices was not given sufficient priority. All my family have been magnificent in their support, not only with ideas for the website, but also in creating it."*



## Jude Shapiro

In March Jude took on the challenge of running 52 miles in memory of her Dad who received hospice care during the last few years of his life.

She had planned to run several races but due to lockdown cancelling many of these she got creative and ran her miles in areas that had connections to her Dad, including Essex where he grew up.

Jude says:

*"Hospices are more than just a place to die – they offer palliative care, specialist pain relief and bereavement support that you can't get in a hospital. And they don't only support the dying but their friends and family as well. I know that my experience and memory of losing my dad to a complicated illness could have been very different without the space and expertise of a hospice environment."*



Jude completed her miles despite being in lockdown and raised a phenomenal £4,054!

Whilst the last six months have focused on responding to the COVID-19 crisis, Hospice UK work has continued.



## Goal One:

Extend our reach and enable hospice quality care to be delivered in any setting

### Hospice quality care, anywhere

#### Erika

**St Elizabeth Hospice in Ipswich and East Coast Community Healthcare (ECCH) joined forces to increase the provision of free palliative care across Great Yarmouth and Waveney.**

Erika Clegg and her mother Rebecca benefited from this service when Rebecca needed palliative care.

*"It really was a breath of fresh air for us when she entered the hospice service, as their support had continuity and we got to know the same faces. They made us feel comfortable and relaxed, which is very hard to do during such a difficult time.*



*"Mum died at home with kind people around her, and that's what she wanted. After mum's passing, the care from St Elizabeth Hospice didn't stop. They contacted me within a few days to see how I had been and to offer further help if I needed it, like counselling and bereavement support."*

### Outdoor spaces support wellbeing

**One of our biggest supporters is the National Garden Scheme, who have donated an incredible £250,000 to Hospice UK so far in 2020. This donation is thanks to over 3,700 garden owners who have opened their gates to raise funds for nursing and health charities.**

Our partnership with the National Garden Scheme has been more important than ever during COVID-19, and their innovative virtual garden tours have meant people can still enjoy their beautiful gardens at home.

#### Karen Mann

Karen Mann has been opening her garden with the National Garden Scheme since 2014.

Karen's son, Jake who had muscular dystrophy and was confined to a wheelchair was able to benefit from the hospice at home scheme at Jake's hospice. His nurse, Bev Barclay, would always schedule her visits for the last appointment of the day so that she would have time to walk around Karen's beautiful garden with her.



While enjoying the garden herself, Bev was also able to see the huge benefits it gave to Karen's well-being and mental health and it was Bev who raised the idea of a public opening of the garden, raising money for hospice care.

When Jake died in 2014, it was the garden that helped Karen through her darkest moments and her decision to open the garden for the National Garden Scheme the following summer gave her a goal to work towards.



*“After we lost Jake, knowing that I had agreed to open the garden that summer, gave me a focus and stopped me sitting around and crying all day. I had committed to opening and had to get on with it. So really, the garden has had a huge role in keeping me going.”*



**“Hospices have given heroic care to people against massive Covid-19 challenges.**

**Everyone at @NGSOpenGardens is proud to support @hospiceuk which has shown great leadership.” – George Plumptre, CEO, National Garden Scheme.**



## Virtual care, day and night

Caroline and Ayla

*“It’s really reassuring to know that any time I need Children’s Hospices Across Scotland (CHAS) they are just a phone call away, and I can access vital clinical advice any time, night or day.*

*“I’ve phoned at midnight and during the day, and they’re always there. If I’m lying awake during the night worrying about something to do with Ayla and need to chat to someone, I know I can phone CHAS.*

*“That truly is a lifeline, especially at the moment as I am extremely worried about coronavirus, given that Ayla already suffers from breathing difficulties and has a weakened immune system.”*

## The impact of hospice care

**The HOLISTIC project (Hospice Led Innovations Study To Improve Care) was commissioned by NHS England in January 2017, with the aim of assessing the impact of hospice interventions on the amount of time that people spend in hospital at the end of life.**

This groundbreaking study not only involves analysis of NHS data to assess the impact of the hospice interventions, but also included qualitative analysis of interviews with local staff, commissioners and patients.

A background paper written by the research team examining the evidence base for hospice led interventions was accepted for publication in the BMC Palliative Care in March 2020.

While the findings have been delayed due to difficulties in obtaining the data needed, we are currently completing the 27 different hospice led interventions included in the study cohort, and will shortly be publishing the research findings.



## Goal Two: Tackle inequality and widen access to hospice care

### Helping people find the care and support they need

Over the past year, 434,000 people searched for information about hospice and palliative care. Thanks to project funding from NHS England we updated our 'Find a hospice' service on our website so that additional services like day care, wellbeing hubs and bereavement help points are recorded for each hospice along with the location of the main hospice site, giving the user a more detailed picture to find the right help.

### Widening access to care

100,000 people still can't access hospice care. Hospice UK is helping to extend the hospice care to those people with unmet need. This year, one of the areas we supported was projects for veterans and their families through a grants programme generously supported by The Aged Veterans Fund.

#### From Rowans Hospice:

A 91 year old gentleman and a former RAF pilot with a diagnosis of dementia joined the veterans' drop-in at Rowan's Hospice to allow his wife to have support from other members of the Living Well Centre team. She is now able to enjoy complementary therapies while he gains support from fellow veterans in an informal setting.

#### Charles Hobbs

Charles Hobbs, known to everyone as Chas, was granted his wish to get married to Shirley by Fair Havens Hospice in Essex, who arranged the service in just 24 hours. Shirley says:

*"Staff went beyond any expectation you could imagine, giving up their own time to help us prepare for our wedding day. The team pampered me, styled my hair, decorated the private garden outside Chas' room and made a cake decorated with butterflies. You can tell they thoroughly enjoy working here."*





## Hospice UK awarded 297 grants between 1 April 2019 – 31st March 2020, totalling £1,146,021

Our Community-led Hospice Care programme, funded through the National Lottery Communities Fund, delivered four exciting projects that sought to find innovative ways to meet palliative and end of life care needs across different sections of society. Each involved piloting new ways of working between a local hospice and community partner(s) to reach specific people with unmet need.

### These four projects are:

- **Compton Care in Wolverhampton** working with South Asian communities to help them overcome barriers that may stop them accessing hospice care and increasing community awareness. This led to funding being secured for a South Asian project in collaboration with Royal Wolverhampton Trust, focusing on patients with a palliative diagnosis of Renal Disease and or Heart Failure, translation of Compton Care leaflets and the development of a South Asian Bereavement Information Hub.
- **A Compassionate Neighbours befriending service** by St Christopher's Hospice in London to reach different faith and ethnic groups. They have obtained a grant to extend this service to the borough of Croydon. Research from the project showed a need for more carer support and Coach4Care was created to get that support from the local community.
- **Hope Support Services** caters for young people looking after a relative with a life-limiting illness. Their grant also contributed to an Outreach Worker to encourage collaborative work between Great Oaks Dean Forest Hospice and Hope Initiatives.

- **Mountbatten Hospice** is the only hospice on the Isle of Wight. Named "Responsible Communities", a befriending service project was set up to engage neighbourhoods on the island to support vulnerable people in the community who are in their last years of life.

*Coach4Care is... "Helping me to think about my future. Not just focusing everything on my father. I'm grateful for that reminder. It's helping me care for him better I'm a bit more relaxed I'm not as stressed I'm still caring but I'm stepping back a bit. I'm trying to enjoy it a bit more in spending time with him."*

**Carer receiving mentoring support**

*"Being a Compassionate Neighbour gives me the opportunity to meet new friends, attend meetings, discuss difficulties or any problems, enjoy coffee and sometimes lunch. More importantly I gain the priceless satisfaction in adding a little happiness to meet the basic need of another person."*

**Compassionate Neighbour volunteer**



## Supporting young people moving into adult services

In September 2019, a three-year project began to consider and address the needs of young people with complex and life limiting conditions as they make the transition from children's services into adulthood. Hospice UK is working with three Transition Networks where virtual ECHO sessions are used to help share knowledge between professionals to support young people moving into adult care.

In addition, Hospice UK is engaging local groups, health professionals, educators and other stakeholders to join a National Transition Community of Practice (CoP) to learn how we can further transform care for young people with complex and life-limiting conditions.

Hospice UK is working in Partnership with Together for Short Lives and the Open University Sexuality Alliance, to ensure that people with life limiting conditions are able to live fuller lives, and highlight the topic of sexuality for this group. This is an area often missing in palliative care services and was brought to the fore at our 2019 National Conference.

Lucy Watts MBE and Leah Booth, both young adults living with complex conditions, gave a powerful and thought provoking talk on research into sex, sexuality and relationships and what matters to young people with complex conditions, which was very well received.

### Adil

*"Going to the hospice's Young Adults Group at St Christopher's Hospice takes away the headache, because they manage things like personal care so parents and carers can go home with their minds at ease. Then I can enjoy five or six hours of chit-chat with my friends!"*



*"There are lots of activities like arts, music and workshops, but they are all optional, and you can choose just to socialise if you want. It gives you some freedom, and you are treated like an adult."*

*"It might be an ordinary thing for most 25 year olds, but I'd never been able to go to a festival or clubbing, so to go to WOMAD with the group last year was amazing."*





## Hospice Care Week

**In October 2019, the ninth annual Hospice Care Week highlighted the theme 'This Is What It Takes'.**

Hospice Care Week is a chance to celebrate hospice care and acknowledge all the work hospices do, whether it is clinical support, bereavement services, keeping the gardens trim, or cooking healthy meals.

The reach of the campaign continues to grow, with 80% of member hospices participating.



**Tweets during the week were seen 370,000 times.**



Hospice Care Week 2020 continues the theme of 'This Is What It Takes', expanding it to reflect the challenges of COVID-19.



## Delivering change

Hospice UK works with all political parties and decision makers in end of life care.

### England



**We provide the secretariat to the All-Party Parliamentary Group (APPG) for Hospice and End of Life Care, which we have been supporting to examine inequalities in end of life care. A report from the APPG will be published in 2021.**

Last year we successfully persuaded the Westminster government to mitigate the impact of a rise in the employer contributions to the NHS Pension Scheme in England, which would have otherwise added approximately £30 million to charitable hospice costs. We worked to ensure that the governments of Scotland, Wales and Northern Ireland also took steps to reduce the impact.

In August 2019, in recognition of the vital work that hospices are doing the Prime Minister announced £25 million in additional funding for hospice and palliative care services. Hospice UK worked closely with NHS England to help design a mechanism to distribute the funding to the frontline quickly and efficiently.

### Wales



**Hospice UK supports work in Wales through our representation by Hospices Cymru on the End of Life Care Board.**

This year, Hospice UK was invited to be a representative on the Welsh Government's Compassionate Cymru Steering Group and secured an advocate for carers of people at the end of life on the Welsh Government's Ministerial Advisory Group on Carers: Engagement and Accountability Group.

Hospice UK supported the Members of the Senedd to hold a short debate on hospice and palliative care in November 2019. In his response to the debate, the Minister for Health and Social Services outlined the completed and outstanding recommendations from the Cross Party Group Inquiry into Inequalities in access to palliative care along with his continued commitment to review the funding of charitable hospices.



## Scotland



**Hospice UK has a seat on the Scottish Government's implementation group for the new definition of terminal illness in relation to benefits, which removes the current six month rule and allows fast track access to benefits for people who are terminally ill.**

We co-ordinated and submitted a joint evidence submission to the Scottish Parliament's Health and Sport Committee's inquiry into social care in February 2020, in collaboration with the Association of Palliative Care Social Workers, Carers Scotland, CHAS, Marie Curie, MND Scotland, Sue Ryder and Scottish Care. The response focused on the need for a responsive, flexible, proactive approach to social care for people affected by terminal illness.

We also called for support for the specific needs of carers for people who are terminally ill when their caring role comes to an end, to be included in the Scottish Government's Carers Strategic Policy statement, and we commented on proposals for a Disabled Children and Young People (Transitions) (Scotland) Bill in January 2020.

Hospice UK, along with Marie Curie and Together for Short Lives in 2019 advocated for Scotland to fully meet the increase in NHS pension costs that hospices in Scotland were facing. In June, the Scottish Government confirmed the funding allocated.

## Northern Ireland



**Hospice UK accepted the invitation to sit on the Regional Palliative Care in Partnership Board, working with the key stakeholders in Northern Ireland in the delivery of palliative care services and responding particularly to the challenges of COVID-19.**

The board's priorities include Advance Care Planning, taking forward a public health approach to palliative care, and support for the no more silos policy. The board is facing many challenges but remains committed to its pre-COVID-19 vision of collaborative working.

The Project ECHO team responded quickly as part of the Health & Social Care Board's COVID-19 response supporting a wide range of networks with the dissemination of key information and gathering information for commissioners and service managers.

Between March and August more than 8,400 care providers participated in 251 ECHO sessions involving a wide range of networks including nursing homes, community pharmacists, district hospital staff linking with GPs, community support groups and many more. The Chief Medical Officer used our services for several of his link ups with clinical teams across the region and our expertise in the skills of running virtual meetings was highly utilised and appreciated across the region.



## Goal Three: Work with communities to build capacity and resilience to care for those at the end of life

### Community care and support Working in partnership

**Hospice UK is thrilled to have been chosen by Deutsche Bank employees as their Charity of the Year for 2020 and 2021. The partnership engages employees through fundraising, volunteering and educational activities, promoting mental wellbeing through educating employees on the benefits of creating a society that talks openly about death, dying and grief.**

Deutsche Bank employees have engaged in a number of fundraising events for Hospice UK, working up to the One Day event in September 2020. This fantastic event encouraged staff from across the company to donate a day's salary to Hospice UK, which is then match funded by the bank.

Money raised helps people who each year go without the end of life care they desperately need. Funds will enable Hospice UK to work across the healthcare system to support innovations that join up vital care from GPs, care homes, hospitals and communities, as well as carry out research and understand new patient needs in light of COVID-19, including physical rehabilitation, bereavement counselling and mental wellbeing support.

Together Hospice UK and Deutsche Bank are building the foundations to lasting positive impact with a commitment to Hospice UK's Compassionate Employers programme, which supports Deutsche Bank employees affected by terminal illness, caring and bereavement to receive support in the workplace.

Over £50,000 has been donated by customers of The Co-operative Bank through their Everyday Rewards Account rewards.

Hospice UK is also proud to have retailers New Look and Joules as partners.

New Look customers have been inspired to donate good quality, pre-loved clothes to their local hospice shop, reducing clothing waste and increasing support for their local hospice. Last year over 250 hospice shops and New Look stores were supported and we hope to expand this in the future. We have also been delighted to receive support through their 'We're Better Together' charity t-shirts and range of face coverings alongside their other charity partners.





# Support in your time of need

## Compassionate Employers

**We understand that everyone will be affected by bereavement at some point in their lives and that this can impact on work. One in three working-age people have long-term health conditions and 56% of people would consider leaving their employer if they did not receive bereavement support.**

There's an urgent need to provide better support for employees who are affected by terminal illness, caring responsibilities and bereavement and it is because of this that Hospice UK have developed Compassionate Employers.

The Compassionate Employers programme equips employers to provide the best possible, and appropriate support to employees, line managers and HR professionals if they or someone close to them are coping with terminal illness, caring responsibilities or bereavement.

In light of the COVID-19 pandemic, and working with our existing Compassionate Employer partners, the workshops are now adapted for online delivery. Looking forward, we will implement a targeted approach to raise awareness of the programme and its themes, and to grow our network of Compassionate Employers.

*"In addition to care given by the healthcare teams there is a need for compassion in the workplace. This is vital, not only for a person's wellbeing and mental health in times of need, but also to grow a culture and work environment where all employees know they are valued and supported."*

**Carole Walford, Chief Clinical Officer, Hospice UK**



## Talking about dying, death and grief

**Dying Matters**

**Dying Matters Awareness Week takes place every May. This is a public-facing campaign to encourage conversation around dying, death and bereavement.**

*'Let's talk about it'*

There were 426 registered events held for May 2019, which included death cafes, cemetery tours and a one-woman play about grief from New York, as well as 418 news items talking about death and dying, compared to 360 in 2018.

In October 2019 we introduced 'I Remember' a digital online campaign that aimed to provide people with a focus on remembering their loved ones. The campaign reached over 11 million on digital channels and it will run again in 2020.

Over 10,900 of our Dying Matters guides to help people understand dying and bereavement were downloaded between January and the end of March 2020.



*"I'd never considered virtual death cafes as a viable option, but we're talking about alternating physical with virtual ones every other*

*month in the future. They're just more accessible for some people.*

*The main goal was to get people talking. It ended up being a really meaningful and really great conversation."*

**Nicole Stanfield Caile, Death Café Taunton**



## Goal Four: Empower a strong, dynamic and responsive hospice sector

### A sector fit for future

Our 2019 November annual conference 'Dying for Change' took place at the ACC Liverpool, focusing on the themes of evolution and revolution with hundreds attending.

Over 90% of respondents rated the event good or excellent.

Conference talks discussed how hospice care can be developed to meet the ever-changing and complex needs of a growing, ageing population through sharing ideas and good practice, and challenging current ways of working.

The Hospice UK Conference is renowned for its awards that celebrates the achievements of hospices over the year. These awards are supported by The National Garden Scheme.

#### Our 2019 awards and winners:

- **Innovation in Care**  
Lindsey Lodge Hospice
- **Innovation in Partnership Working**  
St Mary's Hospice
- **Dying Matters Award**  
Maidstone and Tunbridge Wells NHS Trust
- **Michael Howard Award**  
Arthur Rank Hospice Charity
- **Innovation in Income Generation**  
Chestnut Tree House
- **Tackling Inequalities**  
Birmingham St Mary's Hospice
- **Volunteer of the Year**  
Pat Ross, Highland Hospice
- **Volunteer Gardener of the Year**  
Martin Winn, St Cuthbert's Hospice
- **Dementia Care at Home Award**  
St Giles Hospice
- **Towergate Hospice Team of the Year**  
Wigan and Leigh Hospice

270 posters and 24 oral presentations that explored the future of end of life care made up the poster exhibition and presentations at the 2019 Hospice UK National Conference.





## Hospice care for everyone

**Project ECHO (Extension for Community Healthcare Outcomes) is a virtual system that brings health professionals and end of life experts together to provide education through knowledge sharing and peer support networks that share best practice on real-time cases.**

Since April 2018, Hospice UK's Project ECHO has partnered with Highlands Hospice in Inverness and St Luke's Hospice in Sheffield, and has trained 44 organisations to become 'ECHO hubs'.

These hubs have run over 70 knowledge sharing networks, adapting to support local need and service provision.

Hospice UK has two ECHO teams; one in London and one in Belfast.

### London

Throughout 2019-20, the ECHO team in London supported five Outcome Measures in Practice ECHO sessions to a network comprised of over 150 registered participants interested in sharing and supporting to each other on the implementation and use of Outcome Assessment and Complexity Collaborative Measures in Practice.

In September 2019, the team partnered with the Association of Palliative Medicine (APM) to launch the Hospice Medical Leaders ECHO Network. Over seven sessions, the community of 54 registered Medical Leaders through facilitated discussion provided each other with support to tackle the professional isolation they commonly experience.



### Belfast

The team in Belfast continues to deliver the Project ECHO NI programme for the Health and Social Care Board; over 2019-20 the team has supported 35 ECHO Networks.

Our Evaluation Fellow, Dr Janet Diffin continues to work with ECHO Leads to identify short and long-term objectives of their ECHO Programmes and to gather evidence to support the transformational changes that impacts on service delivery.

The team were invited to 18 events to share the ECHO programme and how it can be used within an integrated healthcare system.

*"Project ECHO enables us to share knowledge and expertise, learning from and with others who support people with palliative and end of life care needs. It sets up communities of practice and learning that supports good care across all settings."* **Carole Walford, Chief Clinical Officer, Hospice UK**

## Support for those working in hospice and palliative care

In April 2019, Hospice UK worked with Health Education England to share the latest information in the progression of the new Nursing Associate role. Over 40 hospices attended to contribute and gain insight into the inclusion of these roles in future workforce plans.

In May 2019, Hospice UK hosted a multi-disciplinary workshop for participants across the sector to share the latest thinking in recruitment and retention of nurses. The workshop enabled peer-to-peer learning about working practices and shared resources. A workforce, education and learning network was established with over 90 representatives across the four nations who now regularly meet to share learning.

Working in partnership with Cass Business School, we delivered the first Masters programme module for Hospice Leadership with 11 students completing the module over three months. We also continued our EAPC Award Winning Strategic Leadership Programme with the Westcott Group bringing the total to over a 100 hospice leaders benefiting from this professional development programme.

We delivered two conferences focused on Fundraising and Retail. Themes concentrated on Legacy Fundraising and why it matters attended by 74 delegates and The Theatre & Drama of Hospice Retail with 96 delegates.

## Clinical Communities of Practice

A Community of Practice (COP) is a facilitated e-network based around common interests that bring together clinical leaders, managers and practitioners across the hospice sector and beyond. Membership of all the COPs has increased in the last year.

**We have seven Communities of Practice. These are:**

- **Infection Prevention and Control**  
A network for best practice and learning for infection control in hospices
- **Palliative Care and Dementia in partnership with Dementia UK** Promotes best practice and learning for practitioners and carers  
National Transition Community of Practice – For young people with complex and life-limiting conditions
- **Education Network**  
Formed to help hospices optimise the potential and contribution of their people to deliver high-quality palliative and end of life care
- **Patient Safety (Clinical Benchmarking)**  
Gathers monthly Patient Safety Data from hospices to support quality improvement
- **Outcome Measurement in Practice**  
Supports hospices to be active with research and outcomes and methodology
- **Clinical Leaders Community of Practice (formerly ECLiHP)**  
Executive Clinical Leaders engaged in strategic planning and delivery of hospice care

*“Palliative care and hospice care is changing. The role of ECLiHP is to provide the strategic clinical voice within palliative care, supporting current and future clinical leaders to manage the challenges that arise.”*

*“Our challenges may be different locally – it is important as a group, and as a network, that we support each other and take those challenges forward.”*

**Erika Lipscombe, Chair of ECLiHP**

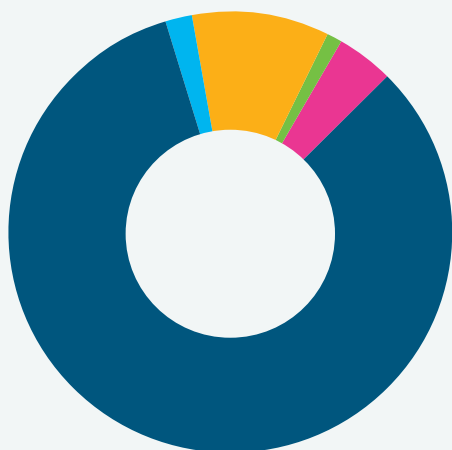


# Finance

## Income

**Our total income for 2019/20 was £6.4m**

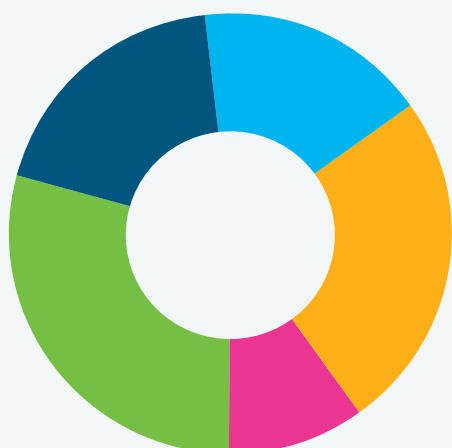
- Fundraising income – 82%
- Investment income – 2%
- Income from charitable activities – 10%
- Income from other trading – 1%
- Membership fee income – 5%



## Expenditure

**Our total expenditure in 2019/20 was £6.5m**

- Extend reach – 17%
- Communities work – 10%
- Tackle inequality – 25%
- Empower a strong hospice sector – 29%
- Costs of raising funds – 19%



# Thanks

**We are incredibly grateful to all the individuals and organisations who support Hospice UK and enable us to do this work.**

The Development Board, Chair – Merrill Powell.  
The London Fundraising Committee  
Trusts and Foundations:

- CSIS Charity Fund
- The Julia and Hans Rausing Trust
- Masonic Charitable Foundation
- St. James's Place Charitable Foundation
- Wolfson Foundation

## Corporate partners

- Aberdeen Standard Capital
- Ageas Insurance Ltd
- AmazonSmile
- Brit Insurance
- The Co-operative Bank
- Deutsche Bank
- Joules Limited
- Miller Insurance
- National Garden Scheme
- New Look
- Northern Trust
- Paperchase
- Raffolux
- Towergate Insurance
- Tyl by Natwest
- Waitrose & Partners

**And our immense thanks to all those who donate to us, volunteer for us, run for us, raise money for us and who choose to leave us a gift in their wills.**



[www.hospiceuk.org](http://www.hospiceuk.org)

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