

Message from our CEO



Our work has continued at a pace over the last year, including our merger with National Council for Palliative Care on 1 July 2017. We know a bold new approach is needed and to confront the taboo subjects of death, dying and bereavement and the merger greatly strengthens our ability to do this. We can now move forward to achieve our goal that everyone and those around them, no matter who they are, where they are or why they are dying or bereaved, gets the care and support they need when and how they want it.

Alongside the merger our existing workstreams and focus have continued, including strengthening the voice of hospice care across the UK

The recruitment of dedicated policy posts in Scotland and Wales has enabled us to make great strides towards this with the publication of new research into the scale and reach of hospice care in Scotland and Wales, and a briefing on the ways in which hospices and care homes are collaborating to improve people's end of life care.

We have also made significant investments in our clinical workstreams over the last year with Project ECHO, one of our most ambitious projects to date, and in the new quality and improvement agenda. More details about these as well as our ongoing programmes can be found in this report.

There is, and will continue to be, enormous strain on our already pressurised health and care systems, the wider business economy and on the families and communities.

Transformational change is needed. We want to bring about the widereaching social and cultural transformation that is needed around how people in the UK are cared for at the end of their life. Our programmes are aimed at empowering individuals, communities and populations to embrace the ethos of hospice care and extend its breadth and reach to improve everyone's experience of death, dying and bereavement.

Tracey Bleakley Chief Executive

Our year in numbers



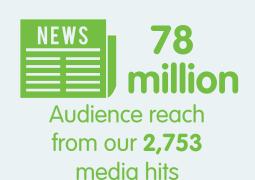


1.9million people reached through our Open Up Hospice Care Campaign











Beyond the walls

Commissioned by NHS England, the Hospice Led Innovations Study To Improve Care – or the HOLISTIC project – is a ground breaking new study into the effect of hospice-led interventions on the use of acute care for people at the end of life.

Involving both qualitative and quantitative components we are working with 24 different hospices around England to take this forward.

The results once published will, for the first time, provide a robust evidence base for the contribution that hospice care can make to reducing the numbers of people dying in a hospital bed unnecessarily.

Project ECHO

One of our most ambitious projects to date, Project ECHO aims to help care organisations across the country reach more people at the end of their life and offer the high quality care they need.

ECHO is about changing the way we work – it is not about adding something new. It is a methodology; a way of working differently to enable better decision making by connecting existing networks and care communities with each other via a central online hub. It will:

- make specialist knowledge accessible whether that is the latest research in a disease or the specialist knowledge of a patient and their family and community
- offer **tele-mentoring** through peer and specialist support to reduce the impact on those working in isolation and ensure better decisions can be taken for the patient.

Build a body of professionals

committed to teaching and learning from each other and to improving clinical decision making across the network.

Ultimately to:

- extend the reach and improve patient care in any setting
- improve staff retention and efficacy
- improve clinical decision making and achieve greater efficiency and benefits for the patient.



Strategic objective 2: Tackle inequality and widen access to hospice care

Access to hospice care is currently inequitable. People with conditions such as dementia, heart and liver failure and frailty would benefit greatly from hospice care but are not widely being referred. Many groups - faith groups, the LGBT community, homeless people, prisoners, Gypsies and Travellers - feel they are disadvantaged towards the end of life with no easy access to appropriate hospice care.

We need to understand who is not receiving hospice care and help local hospices to better understand the needs of their whole community, with access to research into the best services and approaches and education to help them focus scarce resources and respond to unmet needs. A new initiative, funded by NHS England, will see us work with a range of partners to improve end of life care for homeless people, Gypsies and Travellers, and people from LGBT communities.

Findings and resources will be shared in early 2018.

A major new project, supported by the Peter Sowerby Foundation, will be developing and improving patient demographic and hospice activity data. A pilot of a new approach to data and intelligence will be more robust and help hospices make better use of data to develop services and improve the care for patients and their families.



We held a round table event with 30+ participants working with homeless people across London to consider the current challenges and identify key areas for future collaboration.

A grant from the Baring Foundation is enabling us to deliver learning and training events, online forums and other resources for hospice staff to help them understand the implications of and implement the Equalities Act 2010.

Heart failure and hospice care

This publication looks at how people living with advanced heart failure can benefit from personalised palliative care.

This important title, co-published with the British Heart Foundation, in collaboration with the new Wolfson Palliative Care Research Centre at the University of Hull and supported by the National Garden Scheme, also showcases the great work being done by many hospices already to improve end of life care for people with heart failure.

The 2017 St. James's Place Foundation grants programme aims to encourage a hospiceenabled approach to heart failure and support hospices in taking new steps to working collaboratively with their colleagues in cardiology, care of the elderly and other areas of care provision. We received 45 applications requesting more than £1.6 million.

We awarded 17 grants totalling £502,238. Over the next year we will work with projects to help them develop and achieve their goals.

"This is an important and timely guide, and makes a major contribution to improving the way we care for people with end-stage heart failure."

> Dr Mike Knapton, Associate Medical Director, **British Heart Foundation**

Strategic objective 3: Work with communities to build capacity and resilience to care for those at the end of life

Too often the health and social care sector is ill-equipped to support and adapt to situations where traditional family structures are not in place. This must change. Hospice care cannot be delivered without well-supported carers and resilient communities.

Carers play a critical role in caring for someone towards the end of life but this can be very demanding for them. Many have to take a break from work or even give up working entirely.

We have put the challenges facing working carers of people at the end of life on the political agenda, working closely with government officials and other key stakeholders to explore potential options for strengthening the support given to people in the workplace, as promised in the government's manifesto.

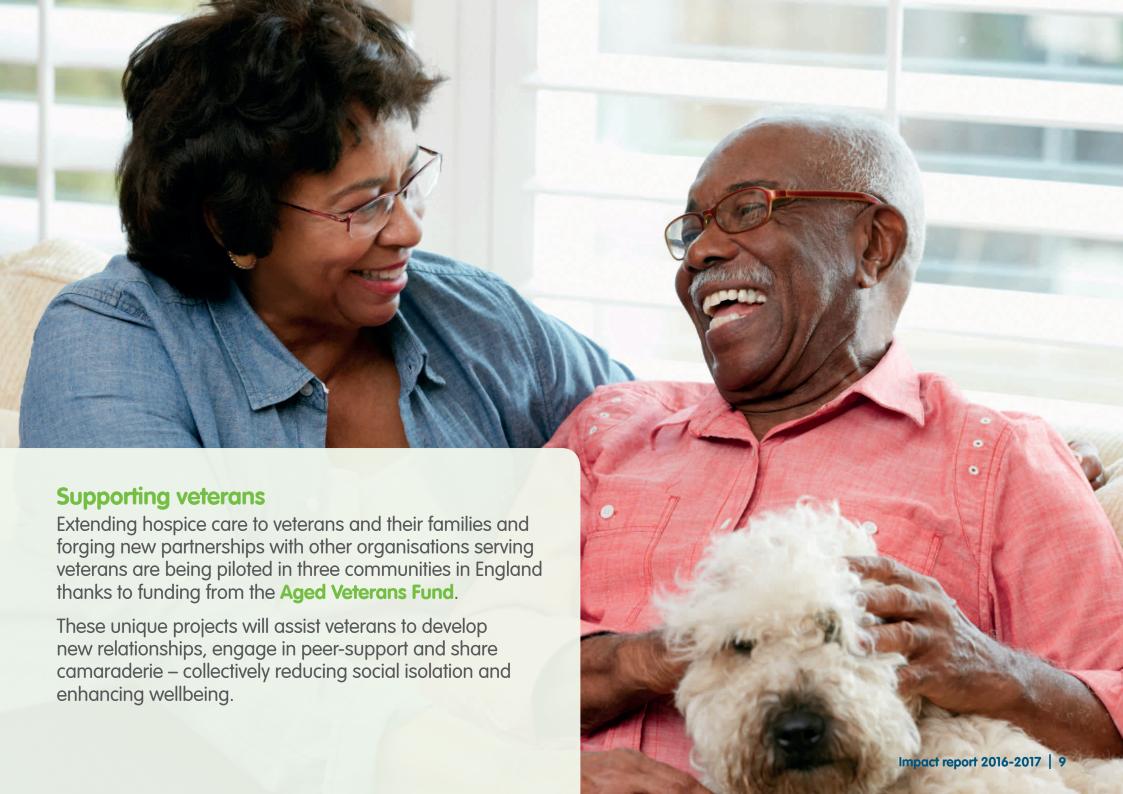
Engaging communities

Informal networks and the wider community play a vital support role for someone at the end of life and those around them. Partnerships with two key funders are helping us to explore how communities can respond to the needs of those around them and pilot new approaches.

Funding from the Big Lottery Fund is enabling the piloting of four community-led initiatives that will demonstrate how people from

communities across England can effectively engage in new and different ways with their local hospices to support the frail and elderly, bereaved young people, carers and those from diverse and disengaged communities.





Improvement and transformation: clinical workstreams

Working alongside hospices, palliative care teams and community leaders we will support learning and development of relevant approaches and methodologies to improve quality across their systems.

The End of Life Care: Emergency Care Improvement Programme,

funded by NHSI, will be continuing across a further eight acute sites to improve the quality of life in their emergency departments and short stay units, and then share this learning through the NHS Emergency Care Intensive Support Teams programme.

Building on the Best – a UK-wide programme funded by Macmillan Cancer Support, aims to provide the support, knowledge and leadership in 10 specific hospital sites in England, three in Scotland and one in Wales. The learning and output from the programme will support improved quality of end of life care in all settings across the UK.

Sharing knowledge and expertise

We have:

- held Tweet chats
- facilitated conference plenaries, workshops and presentations
- facilitated/supported 42 research projects
- published 27 book chapters, journal articles, report and patient information booklets and bloas
- delivered the 'Radical Change Conference', bringing together leaders from across the sector to consider the blueprint for the future.

Supporting the clinical workforce

Workforce planning and development are critical challenges common to all hospices and palliative care teams. Our work aims to build and support leaders, working at all levels to enable them to be effective. resourceful and resilient.

A webinar-based programme offers resources to help leaders build their own resilience and those of their teams. Ten sessions cover topics such as 'Understanding influence and what you can control' and 'Promoting team resilience and exploring trust – a crucial ingredient'.



A new network of strategic HR and Workforce Leads (ShaWL) focuses on building a workforce fit for the future. Working closely with our network of Executive Clinical Leads in Hospice and Palliative Care the group is focused on workforce planning and development.

Funded by The February Foundation, the Dementia Community of Practice has **217 members** and offers networking and peer support to increase knowledge applied to practice and confidence in caring for someone with dementia.

The Wolfson UK bursaries are awarded to nurses, doctors and healthcare assistants working in member hospices or care homes. They contribute towards fees for university accredited palliative care courses such as degree, masters and PhD level programmes. We awarded 321 Bursaries totaling £193,381.





We held our first national campaign to raise awareness of hospice care and draw attention to the gaps in funding and reach. The message: 1 in 4 families who need hospice care, can't get it - 100,000 people in the UK are missing out on vital and expert care they would benefit from at the end of their lives.

The campaign kicked off in July on the BBC Breakfast sofa and was picked up by BBC local radio, **The Times**, the Huffington Post, Diva magazine, and Sky News.

Human stories highlighted the incredible difference that hospices make to someone's life and featured in the MailOnline, The Mirror and The Sun.

This campaign reached 1.9 million people and more than a quarter of a million people watched the campaign video.

Local hospices used the campaign to amplify their own fundraising messages and 58 hospices engaged with the campaign using #OpenUpHospiceCare.

Businesses supported the campaign through the launch of the Open Up Hospice Care Alliance. Huge thanks to Legal & General, Northern Trust and Carillion who ioined the Alliance and thanks also to Travers Smith and Next who donated.

Events included a reception for corporate partners, an event at the **House of Lords** and a gala dinner at the Savoy, as well as a feature in Tatler, helping to raise more than £100,000. Huge thanks to the London Fundraising Committee who made this event possible and will continue supporting us with future events.

Hospice UK is committed to ensuring that everyone and those around them, no matter who they are, where they are or why they are dying or bereaved, gets the care and support they need when and how they want it so the campaign will run again next year www.hospiceuk.org/openup



Strategic objective 4: Empower a strong, dynamic and responsive hospice sector

We must continue to push boundaries, to challenge and provoke and constantly develop and evolve services, partnerships and networks in order to reach and support more people.

Effective leadership and good governance are critical

Over the last year we:

- awarded bursaries of £4,000 each to 12 hospice students to embark on the Cass MSc in Voluntary Sector Management
- ran nine masterclasses as part of our Good Governance Programme and published eight Good **Practice Guides** developed for trustees and senior staff to help them ensure their organisations can survive and thrive in turbulent and challenging times

developed our **Peering Over the** Precipice Toolkit that will aim to support trustees and teams to identify signs of decline and take actions to prevent a crisis.

Demonstrate the outcomes and impact of hospice and palliative care

This is more important than ever and over the last year we have continued to work with the Cicely Saunders Institute and:

 ran workshops and events including two conferences at St Luke's Hospice, Sheffield with the aim of supporting and increasing the understanding and uptake of the OACC palliative care outcome measures

initiated a new dedicated forum on Hospice IQ that is enabling staff from hospices and other organisations to learn from each other, share experience and develop their Community of Practice.

Build capacity, skills and expertise

We launched our **Commissioning** and Strategic Partnerships **Programme** to support hospices negotiate the changing landscape for statutory funding and create new opportunities through collaboration and strategic partnerships.

We offered a bespoke programme of workshops and masterclasses

designed to enhance skills including **'Better Buying'**, run jointly with the Hospice Quality Partnership, to look at ways of reducing costs through smarter procurement.

A future focus will be **General Data Protection Regulation (GDPR)** and training and resources to support hospices in understanding and navigating their obligations under the Equality Act 2010.

We ran a three-day national conference 'People, Partnerships and Potential' that showcased the latest thinking and developments in hospice and palliative care. 800 people joined us for insights and inspiration from leaders and practitioners. 91% of delegates found the event excellent or good.

We delivered two fundraising conferences with the Institute of Fundraising. Topics included fundraising and hospice culture, developing legacy giving and collaboration.

We ran the Hospice Retail Conference, attended by more than 150 delegates and 27 exhibitors. The largest to date, the event highlights the importance of this income stream to hospice care: £55 million in the last financial year towards funding patient care.

We answered over **153 queries** from income generators and members of the public.



Our incredible supporters make a massive difference to our work

Our total income for 2016-2017 was £5.9 million, 83% of our total income comes from our supporters and partners.

People supporting us through their workplace payroll schemes have enabled more than £260,000 to be distributed to local hospices.

Nearly £1 million has been received from people generously choosing to leave a gift in their will and a lasting legacy.

Our first members joined our new Hospice UK Ambassadors programme.

We launched our first ever online shop featuring a range of gifts, merchandise and publications. There have been over 19,000 visitors to the shop so far.

Our incredible and dedicated supporters raised £570,000 to support the work of Hospice UK through taking part in a challenge event. More than 460 people have taken part in an array of challenges; runs, cycles, obstacle courses and overseas adventures. Key events included the 2017 Virgin Money London Marathon and 2017 Prudential RideLondon-Surrey 100.

This year we celebrated the ninth year of our partnership with Clydesdale and Yorkshire Banks. The partnership total now stands at an impressive £5.7 million; that's a remarkable £1,650 every day raised for hospice care and more than 100 hospices supported.

Our partnership with Carillion has raised over £200,000 for Hospice UK and hospices, and their employees

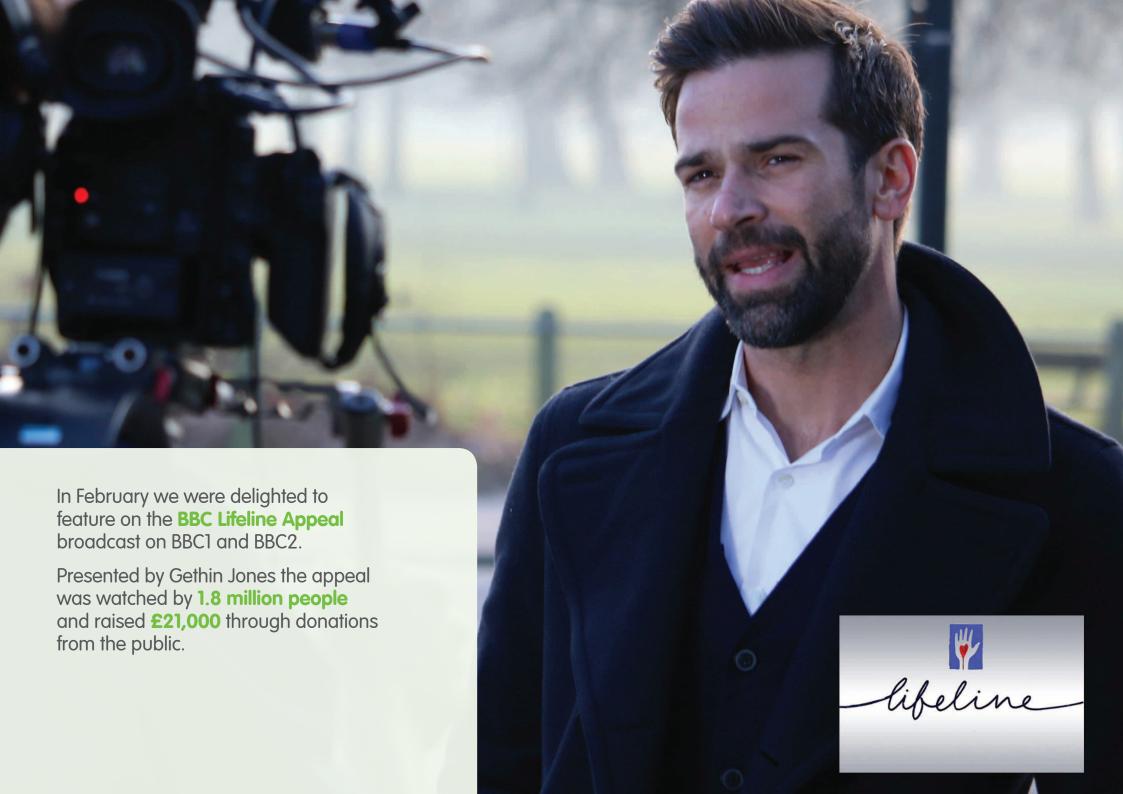
have volunteered over 7.000 hours of their time to support hospices.

Customers of The Co-operative Bank have raised £21,000 for Hospice UK through the Bank's Everyday Rewards scheme.

AB InBev has raised £20,000 for hospice care this year.

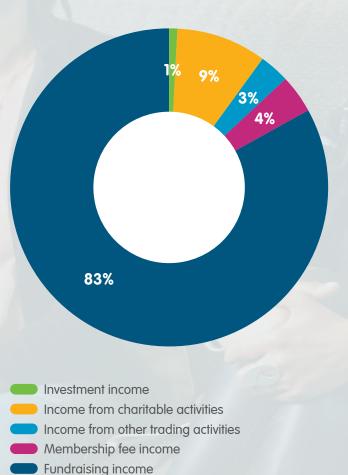
We are delighted to be working with Hill Dickinson as part of a three-year partnership and to secure a new partnership with Joules.

The National Garden Scheme donated £500,000 in 2017 and are supporting a new grants programme for frontline hospice staff as well as the work of our clinical team.



Our income and expenditure

Income



Expenditure

