Making a difference

How Hospice UK has supported hospice care
Welcome

“Our country has every reason to be proud of its hospice movement, recognised as among the very best in the world. In almost every community, local hospices are delivering some of the very best care available to people as they approach the end of life, helping to support people to be cared for, and to die, in the place of their choice.”

“However, demand for hospice care is fast growing, driven by Britain’s ageing population and an increasing number of older people living with complex care needs, as well as young people living for longer with life-limiting conditions. We need urgently to consider how this excellence in care can be radically scaled up to address the crisis of care facing dying people, and help to ensure that more people at the end of life access the support that they so desperately need and deserve.

Hospices are keen and poised to help transform care in hospitals, care homes and other care settings. Hospice UK is playing an important national role in equipping hospices with the knowledge, skills and expertise that they need to support their local communities and to work in partnership with other care providers, but also in giving a collective voice to hospice care, speaking out and championing the change that is needed to improve the care that dying people and those that love them receive.

We are delighted to report on the hugely positive progress that the charity has made in the last year. Hospice UK made a real difference to hospice care, from supporting those providing care to advocating for hospices and raising their profile. This short report celebrates some of our key achievements from October 2013 to October 2014.

All of this is only possible due to our committed members, amazing supporters and volunteers, hard working staff team and dedicated trustees. Our warmest thanks go to everyone who has played a part in our shared success. Together, we can make sure that the contribution made by hospices and the communities that they support continues to drive improvements in the care that people at the end of life, their families and carers receive.”

David Praill, Chief Executive

The Rt Hon Lord Howard of Lympne
CH PC QC, Chair
About Us

One in three people will be touched by hospice care at some point in their lives. Every year, hospices support around 360,000 patients, their carers and family members – both during a person’s illness and following bereavement. Such care aims to improve the lives of people who have a life-limiting or terminal illness, and supports people of all ages who suffer a wide range of conditions – including cancer, heart disease and dementia. Hospice care helps people to live well before they die.

We are the national charity for hospice care. We champion and support the work of more than 220 organisations that provide hospice care across the UK, so that they can deliver the highest quality care to people with terminal or life-limiting conditions and support to their families.

In 2014, we changed our name to Hospice UK. Although the change in name to Hospice UK better expresses the range of hospice care organisations we represent, as well as the diverse and flexible care that they provide and the communities that support them, it does not represent a change in our purpose.

Our aim is simple: to ensure the very best care for everyone facing the end of their life. We believe hospices are critical to achieving this.

By working together, we can ensure the highest quality care for people with terminal or life-limiting conditions, and expert support to their families. Working in collaboration is key to our success, and we look forward to continuing to work closely with all our members and other organisations to achieve our objectives of advocating for and raising awareness of hospice care; promoting and supporting clinical excellence; supporting all those professionals and volunteers delivering hospice care; and supporting the development of hospice care worldwide.

As part of the change to Hospice UK, we have widened our membership. As well as our current membership of local charitable hospices, we are delighted to welcome Marie Curie Cancer Care, Sue Ryder and charities supporting NHS hospices as members.

We are proud of our new name, which builds upon all that has been achieved since we were founded by Anne, Duchess of Norfolk 30 years ago, and opens the door to a new era - one where we can, with greater strength, champion and represent hospice care across the UK, whoever delivers it, wherever it is delivered.
Being the leading advocate for hospice care

We work with our members, politicians, policy makers, the NHS and other charities to influence the development of policy and to ensure a better deal for people at the end of life, their families and carers.

- **Securing a strong voice for hospice care and the needs of terminally ill people in the development of UK government policy** by working in close partnership with government departments, hospice care regulators such as Monitor and the Charity Commission, and the National Institute for Health and Care Excellence.

- **Raising the profile of hospice care with key politicians as we approach the 2015 UK general election**, by working in partnership with a coalition of end of life care organisations to produce a manifesto briefing and engaging key decision makers at the three main party conferences.

- **Building a strong relationship with the Care Quality Commission (CQC) to delay the introduction of the new regulatory system to allow time to develop a specific approach to its regulation of hospice care.**

- **By working closely with other national end of life care organisations**, making significant progress in our campaign to secure free social care for people at the end of life.

- **By supporting the advocacy work of Hospices Cymru, the voice of member hospices in Wales, helping to secure the ring-fencing of central funding from the Welsh Government for three years to 2017/18.**

- **Mobilising over 30,000 staff in local workplaces across the UK in support of hospice care**, through our national partnerships with corporate supporters.

“We have welcomed the opportunity to contribute in partnership with Hospice UK in developing and influencing the approach taken by the Care Quality Commission (CQC) on hospice regulation, whilst at the same time recognising the huge efforts the CQC have made to be inclusive and receptive to the new regime. As a hospice we feel that our involvement in the new process has been very positive, well represented and heeded.”

Judith Park, Deputy Chief Executive, St Luke’s Hospice
As a member of the leadership alliance for the care of dying people, playing a key role in the development of new national priorities for end of life care in England.

Securing commitments by NHS England to further simplify the commissioning and contracting of hospice care, including a national framework for grant agreements between hospices and the NHS in England.

In partnership with the National Council for Palliative Care, securing a wide range of coverage in local and national media about the need for local government health and wellbeing boards in England to give more priority to the needs of terminally ill people.

Providing a voice for hospice care in the development of national palliative care funding arrangements in England, by running four free workshops for adult and children’s hospices in partnership with Together for Short Lives and NHS England and taking part in the national steering group for this work.

Promoting access to pain relief in Europe by bringing together professionals and policy makers through national conferences in four European countries to develop targeted action plans to increase access to pain relief for people at the end of life in their country.

“Our longstanding partnership with Hospice UK enables AXA to make a difference to hospice care locally and nationally. Every pound raised by our employees is a pound that ensures hospice care is there for everyone. We are proud to support a charity that not only provides practical support but most importantly gives a voice to hospices, their patients and families across the country.”

Amanda Blanc, Chief Executive, AXA Commercial Lines & Personal Intermediary
Raising
public awareness

Hospices are rooted in their local communities. An important part of our work is to make sure this continues.

Making hospice care news, securing over 3,000 pieces of coverage in the local and national press. Coverage highlights included:

- Over 3,500 likes, shares and comments from our Hospice Care Week Facebook posts.
- There were more than 4,700 tweets using #HospiceCareWeek.
- Our film has been viewed more than 850 times.
- Together, we reached almost 150,000 people through our Thunderclap to support the week.

By delivering our fourth annual Hospice Care Week, ‘Hospice care, everywhere!’, coordinating efforts with over 100 hospices to raise public awareness about the many ways in which hospice care is delivered beyond hospice buildings: in people’s own homes, local communities, care homes and hospital.

- Over 3,500 likes, shares and comments from our Hospice Care Week Facebook posts.
- There were more than 4,700 tweets using #HospiceCareWeek.
- Our film has been viewed more than 850 times.
- Together, we reached almost 150,000 people through our Thunderclap to support the week.

Our broadcast coverage includes:

Revolutionising the way people access information about hospice care through ehospice. Over 270,000 users access ehospice, and it regularly gets over 40,000 visits every month.

“Carers of dying people face a huge challenge in most parts of the world – ehospice is bringing encouragement and advocacy both to governments and providers of care, in an accessible, timely and relevant way. Reducing suffering through an on-line resource is a tall order – however I believe ehospice does just that.”
“The National Gardens Festival Weekend presents a wonderful opportunity for members of the public to explore a variety of beautiful gardens and enjoy them at their finest during the summer. From urban gardens to Japanese water gardens there’s something for everyone. I do hope lots of people will come and visit NGS gardens… and help support the important work of Hospice UK and the other charities that benefit from the funds it raises.”

Jim Carter, actor

2014 has been an amazing year for our partnership with Clydesdale and Yorkshire Bank, with employees helping to raise more than £300,000 for over 90 local hospices across the UK.

“Our association with Clydesdale Bank has proven to be our most successful corporate relationship. Not only have the staff in the local branches and finance centre been superb fundraisers through the Hospice UK national campaigns but they have also taken part in their own events and used their volunteering time on a regular basis.”

Kenneth Mathie, Fundraising Manager, Accord Hospice

More than 450 people fundraised for us this year, raising more than £725,000 to support our work.

We also supported more than 680 runners and cyclists fundraising for local hospices and Hospice UK with hot meals, refreshments and sports massage at our post-race celebrations at the Virgin Money London Marathon 2014, RideLondon-Surrey 100 and the Bupa Great North Run.

Gardeners help hospice care blossom – our longstanding partnership with the National Gardens Scheme has helped raise over £3million for hospice care.

ITV’s 2013 Text Santa appeal featured footage of many of our member hospices on ITV’s most popular programmes such as The Big Reunion, Jeremy Kyle Show, This Morning and Daybreak.

ITV’s 2013 Text Santa appeal featured footage of many of our member hospices on ITV’s most popular programmes such as The Big Reunion, Jeremy Kyle Show, This Morning and Daybreak.

Giving a fresh, modern feel to our charity through our change of name and complete rebrand for the organisation, including the development of a new, modern and more user friendly website.
Promoting and supporting excellence in care

We empower hospice staff to meet the current and future needs of adults and children with life-limiting and terminal conditions by:

• Supporting over 1,000 people to attend our comprehensive range of conferences and education and training courses for professionals working in hospice care, helping to ensure the hospice workforce is fully equipped with skills they need to provide the best possible care and leadership.

• Connecting over 200 people through our professional networks to help them learn from each others experience and to access peer support amongst care professionals working in hospice care who can often be isolated in their roles.

• Providing one-to-one advice and guidance to hospice professionals and volunteers through our national care strategy and support team, to improve care for people at the end of life and for those facing bereavement.

• Establishing a National Hospice Consortium for education and training, enabling hospices to access funding and expertise in order to deliver more high quality accredited vocational training for non professional care staff working in hospitals, care homes and the community.

• Supporting the development of over 400 doctors, nurses and healthcare assistants working in hospice care.

• Working with St Christopher’s Hospice and the NHS End of Life Care Programme, training 130 nurses in hospitals across England over a two year period, in order to improve the care that people at the end of life in hospitals receive. The QELCA project has gained national recognition for its impact and was nominated for a 2014 Nursing Times award for enhancing patient dignity.

“I know for certain that, as a result of the course, I have enabled patients to die peacefully at home instead of being admitted to hospital.”

Andrew Goldie, Hospice Doctor, Children’s Hospice Association Scotland
• Enabling peer support amongst care professionals working in hospice care, who can often be isolated in their roles, by establishing two popular networks for Executive Clinical Leads, and Infection Prevention Control Leads in hospice care.

• Improving quality and patient safety by developing a suite of audit tools for hospices and collecting and sharing data on patient safety in hospice care.

• By holding a series of expert master classes, in partnership with members, empowering over 100 hospice staff to consider in-depth new ways of developing the best care for patients. Topics have included: harnessing social media to improve care; rehabilitative care; public health, and embedding cultural change when re-designing services.

Over 80 Executive Clinical Leads met in Birmingham for their second annual conference, and explored key issues concerning contemporary leadership in hospice care.

“The presentations were brilliant and the day was just the right balance of talk and tools. The service user’s talk blew me away and no doubt got everyone thinking about the positive power of social media.”

Jane Easton, Communications and Engagement Manager, Richard House Children’s Hospice
• Driving quality by publishing a national definition of quality in hospice care to be used by hospices and other care providers to inform their plans and work that relates to quality.

• Publishing a volunteering toolkit with Together for Short Lives, encouraging the development of volunteering in hospice care, specifically in care-focused roles, and providing the practical tools to do this.

• Delivering tailored training in coaching skills for 20 hospice staff leading clinical teams in hospices, equipping them to manage future challenges and to better support their colleagues.

• Supporting hospices to improve how they gather patient, family and carer feedback on their experiences of hospice care, through our real time reporting project.

• Through a five year partnership with the African Palliative Care Association, reducing restrictions to the availability of pain and symptom-controlling drugs and improving access to, and quality of palliative care services across six African countries.

• Promoting the development of children’s palliative care through a five year project with partners in India and Malawi. By July 2014, six new palliative care services had been developed, and the project had reached over 4,200 children.

• Driving thought leadership in the sector through our annual conference, attended by over 600 people, which provided a platform to consider the recommendations of the Commission into the Future of Hospice Care. The conference also enabled delegates to share learning from 175 poster presentations and for their authors to have abstracts published in a peer-reviewed journal.

We also held seven pre-conference master classes reflecting themes of the Commission into the Future of Hospice Care. Led by high-calibre facilitators, each master class provided an opportunity for intensive and interactive learning, attended by 147 hospice staff from a range of disciplines.

“The launch of the Commission’s report and then the opportunity to drill down into what it means for every person and service represented at conference; we were encouraged to really unpick not just the implications, but also how they translated into action.”

“Excellent interactive facilitation. Outlined the need to interrogate what hospices do and why.”
Total grant amount awarded to hospice care in 2013/14 was £930,000*

*During this period, we also continued to manage the £60 million Department of Health/NHS England capital programme for hospices in England.

**Our Grant Programmes**

From October 2013 to October 2014, we have worked in partnership with charitable trusts and foundations, corporate partners and Government to develop our grant programmes.

**Amount awarded**

**£930,000***

**Our Focus**

Our Focus:

- Over £237,000 to support the education of hospice and palliative care staff
- Over £365,000 to support hospices to construct and refurbish their buildings and to purchase vital equipment
- Over £325,000 in project grants to support hospices to develop their care services

**Impact**

- Driving innovation, learning and knowledge-sharing
- Developing the expertise and skills of current and future leaders of hospice care
- Building the skills and knowledge of the hospice workforce to better meet future care needs
- Empowering local services to evidence their impact and contribution
- Improving the physical environment for hospice care

**With thanks to our supporters, including:**
Supporting those providing hospice care

We provide wide-ranging support for all those providing hospice care – from trustees and senior leaders, to staff responsible for raising income, working with local communities and delivering care.

- Investing in hospice care with around £2 million support going directly to local hospices through our grants programmes and national fundraising partnerships.
- Enabling hospices to compete successfully for funding through our commissioning support programme.
- Sharing learning to support the spread of innovation and good practice across the hospice sector through our active programme of courses, conferences and learning events.

“The course materials and the tutor went a long way in helping us to win the bid. The tender process required lots of information, but delivered in a succinct manner – which was quite alien to us. At the workshop, we learnt how to achieve this, and a lot about the expectations of commissioners. If we had not had the benefit of that experience, I am sure the team would have struggled to pull the bid together.”

Julie Halliwell, CEO of Springhill Hospice – participant on our Bidding for Statutory Funding workshop. Springhill Hospice were subsequently awarded a three year, £3.5 million contract to deliver a new integrated end of life and palliative care service for Rochdale.

- **In an increasingly competitive funding environment**, equipping hospices with the skills to bid for and win contracts to support people at the end of life in their local communities through our Commissioning Support Programme. Our Bidding for Statutory Funding workshops have had 100 attendees from 75 hospices.

- By delivering pioneering management and leadership training, **investing in current and future hospice leaders and trustees**, preparing them to embrace future strategic challenges for hospice care.

- **Driving innovation in hospice fundraising**, by running a joint conference with the Institute of Fundraising for hospice fundraisers, as well as three digital fundraising seminars in partnership with JustGiving. Over 150 people attended our annual hospice retail conference in April 2014 to network, share good practice and learn from each other.
• Training and mentoring nine health centres and 225 community volunteers in partnership with Island Hospice Service in Zimbabwe to extend holistic palliative care and bereavement services into rural communities. By May 2014, the project has provided bereavement and young carers support to over 200 children, and also reached over 200 people living with HIV.

• Building mutual support across the sector by enabling people to come together, discuss strategic challenges, and exchange ideas and practice through two new professional networks for staff from member hospices: the first for those interested and involved in hospice community engagement and development, and the second for directors of fundraising and income generation.

“Really exciting day. Very good overview of policy. Great food for thought with innovation and a great sense of all that Hospice UK do.”

• Providing benchmarking reports and programmes to enable hospices to understand trends in their own performance and learn from comparing themselves against others. Our Hospice Accounts report has been downloaded nearly 500 times in 2014. We run a clinical patient safety benchmarking programme, and in partnership with third parties with specialist expertise we offer an annual staff survey and benchmarking report for hospices, and a pay and rewards benchmarking report. In 2014 we introduced an In-Memory giving benchmarking programme.

• Improving the understanding and use of data and outcome measures to drive improvements in hospice care.
  - Working in partnership with the Cicely Saunders Institute to develop new ways to support hospices to implement outcome measures and use these to demonstrate and improve care. This is part of our work towards the development of a hospice outcomes framework.
  - Working with the National Council for Palliative Care and Public Health England to improve the current national data captured on specialist palliative care, through developing better and more relevant questions and more accessible reporting of findings.

• Driving forward and providing national expertise to key discussions about strategic issues in hospice care through our ongoing visits and engagement with our members. In May and June our annual roadshow series saw our senior staff come to discuss key issues with over 170 hospice leaders and trustees in each region of England, and in Scotland, Wales and Northern Ireland.

• Supporting hospices to employ an effective workforce in an increasingly competitive recruitment market by advertising more than 580 posts in the UK through our ehospice jobs service.

“Fantastic that Hospice UK gets out on the road. Providing a chance to mull over key issues with wider peer group is very useful.”
Looking ahead

In 2011, we established the Commission into the Future of Hospice Care to explore key challenges facing hospices and to help them to anticipate and to meet the needs of their local communities.

The recommendations of the Commission, which concluded in October 2013, provide an important framework for hospices to thrive as a sustainable solution to the growing need for end of life care, and to play a leading role in the provision of such care.

In response to these recommendations, we are introducing a comprehensive new three year programme of activity, which aims to build the capacity, capability and sustainability of hospices into the future. This will include:

- **Tailored leadership and management training programmes** to develop the expertise and skills of current and future leaders of hospice care.

- **Grants programmes and the development of peer networks** to build the skills and knowledge of the hospice workforce in order to better meet future care demands.

- **Identifying and sharing good practice and innovations in hospice care** to extend the reach of hospices and to improve the quality, efficiency and effectiveness of the care being provided.

- **Developing national frameworks and tools** that will enable local services to evidence the impact and contribution of the care they provide to local decision makers, funders and commissioners.

What does hospice care mean to you?
Why be a member of Hospice UK

As a member of Hospice UK, you are part of a national movement which promotes, supports and leads hospice care in the UK. Here are some of the benefits of working alongside us as a member.

Be part of the national voice

Hospice UK provides a strong, united voice at a national level, to speak to government and other leading organisations and bodies about hospice care.

Members are directly involved in our policy, influencing and advocacy work. Our voice is reflective of our members, who we engage with through consultations, reference groups and advisory committees.

As a member of Hospice UK, your views and concerns are reflected at a national level.

Did you know?

As a member of Hospice UK you receive a wide range of discounts on essential services

- 10% off ACEVO membership, and no joining fee – saving up to £79
- Free print subscription to BMJ Supportive and Palliative Care
- 20% off selected Oxford University Press publications
- Free membership to CharityComms – saving you up to £3,249
- Discounted advertising on Guardian Jobs
- Free or discounted attendance at GOV Today events
- Free places at London Business Forum events, until March 2015 – saving you £250

Improve the care you provide

Our care strategy and support team are committed to providing practical support to clinical staff in hospice care. Members can access this in a number of ways, including through our professional network ECLiHPC (Executive Clinical Leads in Hospice and Palliative Care), which works to support and improve the leadership of those in patient-facing roles.

Stay informed and connected

Members receive exclusive information and intelligence relevant to the hospice world, such as newsletters, reports, briefings and guidance documents.

We also connect hospice staff with shared professional interests to enable networking, sharing of new ideas and peer support.
Develop your skills and knowledge

Our wide range of courses, conferences, learning events and workshops are open to members – often at a free or discounted rate.

Benchmarking care

Our benchmarking projects are exclusive to members of Hospice UK – enabling members to compare themselves with other hospices and sometimes the wider charity sector in order to develop their services.

Access new funding

Members of Hospice UK receive practical support in the form of funding from our grants programme and our corporate partnerships.

Our corporate partners work with local member hospices by forming local relationships; enabling members to access new funding and enhance engagement with their community.

Did you know?

As a member of Hospice UK, you govern and influence us

- 75% of our Board of Trustees are drawn from, nominated and elected by our members
- Members attend and vote at our annual AGM, influencing our strategic direction
- Members influence our work programmes and priorities through expert committees and other project steering committees.
- We have an Advisory Council and a Forum of Hospice Chairmen with representatives elected and nominated by members.
This report focuses on our achievements from October 2013 to October 2014
Revolutionising the way you access hospice, palliative and end of life care news.

ehospice is a free app and website that brings you the latest news, commentary and analysis on hospice, palliative and end of life care. At the touch of a button, you can access the expertise and experience of the hospice and palliative care community, in the UK and globally.

Visit www.ehospice.com/uk
or download the app: www.ehospice.com/apps

ehospice is a registered charity. The UK edition is managed by Hospice UK.