Despite indications that 81% of people in England wish to die at home (Office for National Statistics, 2016), as many as half of all deaths (46.9-50.3%) occur in hospital (Bit.ly/PHEEolProfiles). In a survey of 21,320 bereaved carers in England, most believed their loved ones would have preferred to die at home, with only 3% saying they would have chosen to die in hospital (ONS, 2016).

Relatives of people who died in hospital rated care significantly worse than for any other place of death, with 31% rating it as fair or poor, which was lower than for any other end-of-life care environment, including care homes, people’s own homes or hospices (Fig 1). A particular concern was that informal carers rated hospital nurses as least likely to “always provide dignity and respect”, with only 53.6% saying hospital nurses always provide dignity and respect, compared with 85.7% for hospice nurses (ONS, 2016).

As the general population ages and the pressures on the NHS increase, Public Health England estimates a doubling of people aged over 85 requiring palliative care, from 150,000 a year in 2020, to 300,000 by 2040 (Etkind et al, 2017). This begs the question, how can the healthcare system, particularly acute hospitals, respond to the challenge of rising demand for end-of-life care, while ensuring high-quality and greater individualisation of care for people who have only weeks or days to live?

Learning from hospice care
Historically, evidence of better care in hospice environments has led to attempts to replicate hospice care in hospital settings, but this has not always been successful. The controversy surrounding the Liverpool Care Pathway – first formulated in the 1990s at the Royal Liverpool University Hospitals NHS Trust and the Marie Curie hospice in Liverpool – is a salutary example of how challenging this can be (Neuberger et al, 2013).

As a result, confidence in hospital-based end-of-life care has been eroded. For example, the Neuberger review highlighted the shortcomings of the...
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Liverpool Care Pathway, More Care, Less Pathway (Neuberger et al, 2013), and evidence on end-of-life care submitted as part of the Francis inquiry on care failings at the Mid Staffordshire NHS Foundation Trust. The latter said: “in the end, the truth was uncovered mainly because of persistent complaints made by a very determined group of patients and those close to them” (Francis, 2013).

Subsequent reports, One Chance to Get it Right (Leadership Alliance for the Care of Dying People, 2014) and Ambitions for Palliative and End of Life Care (National Palliative and End of Life Care Partnership, 2015), highlighted the importance of staff making time to talk to patients who are dying and to respond to their concerns – promoting a patient-centred, holistic model for end-of-life care.

Responding at trust level

For the NHS as a whole, these were defining moments, and at The Princess Alexandra Hospital NHS Trust, they were among the factors prompting a change in how the trust manages end-of-life care. Princess Alexandra Hospital is a 414-bed district general hospital serving a population of 350,000 in east and north Hertfordshire and west Essex. In October 2016, the palliative care and patient experience teams came together to address the issue of end-of-life care, intent on promoting more holistic ways of working. Greater impetus was given to this by:

- A Care Quality Commission report in 2016, saying the trust’s end-of-life care required improvement (CQC, 2016);
- Complaints received from bereaved families about non-clinical staff.

This was accompanied by a series of chance events that offered an unusual insight into what we could do differently. Briefly, the patient experience team were asked to sit with a patient receiving end-of-life care, who had no family or friends. We established a rota and were present for several days until the patient unexpectedly recovered and returned to his care home. One member of staff continued visiting the patient after discharge, and developed a strong bond with the patient. A few weeks later, he was again admitted and died; his situation highlighted the importance of having people present at the end of life.

Our starting point

The CQC report said some patients at the end of life lacked a clearly defined end-of-life care plan and that patient experience feedback showed evidence of behaviours among non-clinical staff that were not consistent with high standards of end-of-life care (CQC, 2016). Questions the trust needed to address included:

- What did non-clinical teams and individuals understand about their roles in end-of-life care?
- What training had they been given to respond to these needs?
- How could the service embed a long-term approach to change and bring in the widest possible range of supporters/caregivers to enable improvement?

Generating ideas using World Café

To answer these questions, the review teams identified an approach that brought the different teams and disciplines together to look at innovative ideas for improvement. World Café is a way of bringing the collective knowledge, intelligence and wisdom of a group to bear on a question in an iterative way (Hurley and Brown, 2009). Individuals from different disciplines meet to focus on a specific challenge, with an emphasis on ‘conversational leadership’, in which conversations are a way for staff to discover what they know, resulting in new ideas. Each ‘café table’ is given a theme; we chose themes around four dimensions of wellness: spiritual, emotional, physical and social aspects of end-of-life care.

Twenty-six people joined the workshop and participants circulated to a new table every 15-20 minutes. Each discussion was led by a table facilitator, who explained what the previous team had come up with, building up a store of ideas connected to the theme. At the end, participants were asked to vote for the ideas most likely to succeed and the results were written up and circulated to the group.

End-of-life volunteers

The workshop was effective, and many of the ideas came to fruition. One was a training module for non-clinical staff based on a humanistic model of thinking, with the focus on staff-patient interactions and sensitive communication. Participants said that non-clinical staff should understand:

- What physical changes to expect when a person is dying;
- The need to give space to patients and families to talk about how they are coping;
- How to recognise what gives patients joy and purpose in their life and enable continuation of this within the limitations of their illness.

This then provided the foundation for a more significant idea that challenged established ways of working. Participants proposed that end-of-life volunteers could be a valuable addition to the service to spend time with dying patients who have no friends or family able to support them on the wards. This would require the following:

- Exploration of successful models elsewhere;
- Enlisting the support of local hospices in developing a successful service and learning from their experience in maintaining large volunteer services;
- An emphasis on screening, selection.

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![Fig 1. Overall quality of life care, England 2015](image-url)
and training to develop a group of insightful volunteers who can offer time and support to patients and families;
● A robust system of supervision and support.

Making it real
Logically the next step was to introduce the volunteer role. However, we quickly established that the level of screening, selection and training of the volunteers at the standard required was beyond the capability and capacity of the specialist palliative care team or voluntary services. As this work was a service improvement initiative, ethical approval was not required, but we needed to look beyond the trust to find a team or exemplar we could learn from.

We discovered that a neighbouring hospital in east Hertfordshire had already introduced an end-of-life volunteer role and could offer the experience of screening, selection and training appropriate for such a sensitive role. We contacted Liz Pryor, who had worked with the team on developing the role at the Lister Hospital and is now founder and director of the end-of-life charity, the Anne Robson Trust (ART), and Jo Corscaden, her colleague at the charity, who subsequently took on the role of Butterfly volunteer co-ordinator at our trust.

Liz Pryor is a tireless campaigner for improvements in end-of-life care born out of her own personal experience relating to the death of her mother. We all have a story to tell, but not all of us have the courage to tell that story, still less to turn it into lasting and meaningful social change. Less than a year after she founded ART, the charity won two national awards for its work.

Our involvement with Liz Pryor and ART has resulted in a memorandum of agreement through which our trust has a formal support and development relationship with the charity for three years. As the first trust to work with ART, we were supported to recruit an invited cohort of trained volunteers and a coordinator (Jo Corscaden). The trust now employs its own Butterfly volunteer coordinator, Nicki Harris, who is rapidly building on the years of voluntary effort put in by ART and is into the second round of recruiting Butterfly volunteers (we now have 37). The boundaries of the Butterfly volunteer role are carefully defined. Volunteers are not there to provide clinical or personal care or offer a counselling service. Their role is to be:
● A comforting presence, when no one else can be, at the end of life;
● Someone to talk to when patients, families or carers may be lonely or frightened;
● Available to run errands, or simply make a cup of tea, for families who are worn out or need a break.

It took a year to bring the idea to fruition and it is now almost two years since Butterfly volunteers did their first shift at our trust in November 2017. A first-hand account from one of our Butterfly volunteers gives an idea of the role and the difference these volunteers can make to patients and their families in the final days and hours of a patient’s life (Box 1).

Outcomes
We collected quantitative and qualitative data through daily reporting and amalgamation of these statistics at the end of every month in a feedback form commonly used in patient experience activity. This documented: volunteer name, patient name, ward, date, shift, time spent, number of drinks made and free text feedback. The simple facts and figures below show the difference the volunteers are making to patients and their families:
● Since the scheme began in earnest in early 2018, volunteers have made 1,535 visits to patients at the end of life;
● Volunteers have spent 819 hours of time by the bedside, including with families and carers, or providing respite to patients who had no one else there for them;
● There have been hundreds of messages of positive feedback from families, carers, and members of the public, some of which can be found on the ART website (Bit.ly/ARTTrustTestimonials).

Future plans
Working alongside ART as its first partner hospital, we are keen to share our learning, as we believe the findings can be generalised and applied to other hospitals. We are therefore offering support to other hospitals interested in implementing this scheme. As a result of the passionate, campaigning focus of ART, the scheme is now on its way to being adopted in many more hospitals in the east of England and London. A number of hospitals are currently implementing the project and as many as 15 have expressed an interest. We also believe the scheme has wider implications for volunteering and end-of-life care across the whole of the NHS.

References
Bit.ly/PegasusWorldCafe
Leadership Alliance for the Care of Dying People (2014) One Chance to Get it Right: Improving People’s Experience of Care in the Last Few Days and Hours of Life. Bit.ly/LACDPOneChance

Box 1. Story from a Butterfly volunteer
My name is Joy Addison. The Princess Alexandra Hospital offered me an opportunity to be trained by the Ann Robson Trust to provide support to patients at the end of life in a hospital setting. Most of us will have someone close die in hospital, and it is not always possible for family or friends to be there. I wanted to make that part of someone’s life easier in whatever small way that I could. On one particular shift, I checked in on a patient. Her daughter was in the room and very unsettled. She told me she didn’t want to be there at the end, and to have “those horrible memories”. I asked if she would like a hot drink and said we could sit in the room with her mum for a while. I asked if it was OK to sit next to her mum and hold her hand so she knew we were there. The daughter relaxed a little, sat closer to her mum and took her other hand. We sat either side of the bed, the daughter telling me about her family. Her mum’s breathing got slower, we were able to acknowledge this together, and to prepare for her death. Her mum died very peacefully with her daughter holding her hand. The daughter was so proud to have been there with her mum. When it was time to go she said, although she felt extremely sad, she was pleased she had stayed with her mum, rather than going home, anguishing over what she had thought would be an awful death. She told me that she felt she needed to tell everyone that death is not to be feared – that it can actually be a peaceful experience.