

Share your Fab Stuff! #FabAwards23

Title of innovation / initiative

- *Summarise your innovation / initiative – try to make it engaging!*

A hand to hold. A listening ear. The presence of another person. These simple things become invaluable in the final days and hours of life.

TNT Award Application

Problem

- *Please clearly and concisely describe the problem that you were trying to solve.*

Too many people die alone, with no friends or family at their side.

The Anne Robson Trust's vision is that everyone receives the compassion and companionship they wish for at the end of their life.

Overstretched resources in care settings, combined with an increasing number of deaths in England and Wales (approaching [600,000 per year](#)) have led to severely compromised end of life care. Even with Covid restrictions relaxed, far too many people spend the final days of their life alone and scared, without the companionship of another person.

Just under [50% of deaths](#) occur in hospital, many with no visitors at all. Busy ward staff and specialist palliative care teams do their very best to try to ensure that every patient has the best care in the last days of their life. The reality is that often this doesn't happen due to overstretched staff, and, as mentioned previously, the sheer number of people who are dying in hospital.

While many services exist to support those who are bereaved, there is very little support available to help people cope in the period *before* someone dies.

“End of life care across the UK is hugely variable and in some places almost non-existent. The Anne Robson Trust makes a valuable contribution in this most sensitive and delicate of areas. This charity, which has only been running for a few short years, has established itself as one that provides the highest standard of care. Within such a short space of time it has a reputation for delivering on its promises”.

Dr Peter Carter, OBE, Trustee of the Anne Robson Trust

Aim

- *What were you trying to achieve? Try and make it specific - how much and by when?*

Anne Robson was our founder's mother. She died in 2010, just hours after being discharged from a week's stay in hospital, which she spent alone unable to see her family. In the hope of creating something positive from this terrible experience, her daughter Liz Pryor began working in NHS hospitals to improve provision for people at the end of their life. She set up the Anne Robson Trust in her mothers' memory, in 2018, and was awarded an MBE for services to end of life care in July 2022.

The charity provides emotional support to people nearing the end of their life, and those caring for them. We work closely with hospitals to help them set up volunteer teams to provide companionship to patients dying in hospital. We also run a telephone support service – giving people from across the UK somewhere to turn to when they have a terminal diagnosis themselves, or are caring for someone who is dying.

Our aim is to work with as many NHS trusts as we can to provide this support for people who are dying, and for their visitors. We also know that the service provides much needed support to ward staff. They would like to have the time to sit with patients who they know are dying, but in reality they just can't. To have a team of specialist volunteers to call on makes the world of difference to them.

One staff nurse told us recently "I care for at least 15 patients at a time, and on numerous occasions I've known that one of them is dying but have been unable to sit with them and hold their hand, as I would like to. I just don't have the time. To know there are volunteers I can call on to do this, when I can't, makes the world of difference to me. I used to go home at the end of a shift and cry. I don't do that anymore because we have Butterfly Volunteers to help us".

Plan

- **What did you do and how did you do it?**

The thought of dying alone is unthinkable to most people.

The amazing volunteers make the world of difference to the patients they support, as well as giving their visitors a much needed break from the bedside, and someone for them to talk to as they sit by their loved one in the last hours of their life.

The volunteers don't provide nursing or personal care. They are literally a human being sitting with another human being as they near the end of their life.

They can read to the patient, play music, hold their hand, gently brush their hair or just sit quietly so the patient knows they're not alone. They provide a real strength to frightened family members who have never sat with someone who is dying before, let alone a beloved member of their family or a dear friend. The volunteers will sit alongside the visitor to ensure they know what's happening, and understand that what they are seeing and hearing is part of the normal process of dying.

They will advocate for patients and visitors – approaching busy ward staff if they feel the patient is in pain, or uncomfortable in any way. Families and friends often find it hard to approach staff as they are so busy, and they don't like to interrupt them.

The benefit to nursing staff of having a specialist team of volunteers to call on is massive. They tell us that it makes their job so much less stressful knowing there are people they can call on to sit with their dying patients.

"We recently had an end of life patient whose family were too distant and elderly to visit. When the lady died, her family were worried that she'd been alone. Being able to tell them that a Butterfly Volunteer had been there with her was a huge comfort to the family". **Ward Manager**

- **How does it work?**

Our aim is to encourage all NHS Trusts to set up a team of specialist volunteers to provide support to patients who are nearing the end of their life. We know how busy NHS staff are, so we provide all the training and support a new coordinator will need – in order that the start of the new service doesn't pull on already overstretched managers.

In a nutshell we:

- Provide an MOA for signature
- Help to secure funding for a dedicated coordinator* (see Resources section) by providing a template business case, and on occasion we submit joint funding bids to grant makers
- Provide a detailed role description for the coordinator.
- Help with shortlisting and interviews for the coordinator – providing all relevant paperwork

including interview questions and scoring criteria.

- Provide a 2-day training package, which is flexed depending on the experience of the successful candidate.
- Provide a full package of all template project documentation.
- Provide support to the coordinator to recruit and train their first cohort of specialist volunteers.
- We facilitate a virtual meeting every month so coordinators can share their challenges and successes.
- We invite all specialist end of life volunteers to join our volunteer community, so they can meet other like-minded people across the country.

For more information, please see the graphic attached. (End of Life Volunteer Leaflet).

The Anne Robson Trust has the experience of supporting NHS Trusts and their volunteer coordinators who in turn then recruit and train a robust cohort of specialised volunteers to support our end of life patients and their families. The training provided to get this initiative off the ground is exemplary and as a hospital who has not had this service before, we have found it incredibly helpful and supportive. It's a pleasure to work with the Anne Robson Trust team!

Voluntary Services Manager

Benefits

- ***What were the benefits of the innovation / initiative for patient experience, staff satisfaction, health outcomes and costs?***

We are working with 18 NHS Trusts, helping them set up and run teams of 'end of life' volunteers.

11 active teams in acute trusts
2 community trusts in set up stage
5 acute trusts in set up stage
10+ more organisations looking to work with us

This work will impact many thousands of patients and their visitors, as well as care home residents and people dying at home.

To date we have enabled 10,800 patients & their visitors to receive support in the last days of their life.

In the last year we have trained 7* 'End of Life' Volunteer Coordinators, and helped embed and deliver training for 200 specialist volunteers.

Since 2021, we have received over 6,500 webpage views for information and resources designed to help health professionals.

"It is my privilege to put on my purple T-shirt and head off to the hospital every Thursday to support patients at the end of their life. Every week I gain so much from being a 'Butterfly Volunteer', far more than I could ever give. I am truly grateful and honoured to do this role." **Butterfly Volunteer**

Although our help to set up and run a service costs us approximately £5000 per NHS Trust, our support is offered completely free of charge to organisations. We use the data provided on a monthly basis by each NHS trust to use in funding applications to support our work, and eventually to expand to more parts of the UK.

Hospitals that have active teams of 'end of life' volunteers have reported a noticeable reduction in end of life related complaints. Families feel cared for once the volunteers start providing support to them, as they have that most precious commodity – time – something that staff simply don't have.

Some of the hospitals we are working with have received glowing responses following CQC Inspections, and their ratings have improved on the back of the support provided by the teams of Volunteers.

“It wasn’t until I got home with his belongings and found the volunteer visiting card that we realised Dad was not alone in the hours before he died. It gave us peace of mind to know that. As a family we really appreciate the support you and your team have provided. Thank you from the bottom of our hearts”. **Relative**

- *If you can quantify the improvement or savings please also include numbers – this can help others produce a business case. If you have patient or colleague quotes, you can also include these here.*

Resources / team

- ***What are the biggest challenges to setting up the service (equipment, budget etc)?***
Our best practice model is that this specialist service needs to have a dedicated volunteer coordinator* to oversee the set up and smooth running of the team on a day-to-day basis. We work closely with organisations to help them find innovative ways to overcome the challenges of securing funding for this post. We are making great inroads into this across the country, with trusts joining us from as far afield as Cornwall, Tyne & Wear, Sussex, Norwich and St Helens, and everywhere in between!
*We understand that it is challenging to find funding for a new post in the current climate. If NHS Trusts have a member of staff who has capacity to run a service (it's a full time job!) already employed, we will provide them with training to set up a team of volunteers.

- ***Who is involved in getting the service off the ground?***
From the outset of working with a new NHS Trust we ensure all the relevant multi-disciplinary teams are involved in the conversation and have a sense of ownership and engagement with the new plans. This includes members of staff from Specialist Palliative Care, Voluntary Services and Patient Experience, as well as the Chaplaincy and Bereavement teams. We encourage engagement with senior management including Chief Executives, Chief Nurses and End of Life/Palliative Care Nursing Leads and Consultants.

Once funding is secured, and a dedicated coordinator is recruited, we will train them to project manage the service from the outset. We are keen that setting up this service shouldn't pull on the already stretched teams in the hospital. Whilst we don't line manage coordinators, we are on hand to advise and guide them whenever required.

- ***Did you use evidence or build on ideas from other trusts or organisations?***
The fact that we work alongside numerous NHS Trusts, who all work slightly differently, enables us to keep the services up to date and relevant. We know that our model works but there is always room for improvement and working with lots of different teams allows us to learn from each other, and continuously help everyone in the group provide as good a service as they can. To this end we have created a community of 'End of Life' Volunteer Coordinators who meet virtually on a monthly basis to share best practice, and discuss and overcome challenges that arise.

We collaborate with a diverse group of other charities to ensure they are aware of our support services to help compliment and build on ideas. We also do this by providing training opportunities to upskill their staff and volunteers. These organisations include Cruse, Age UK, AgeSpace, Carers in Herts, Carers in Devon, Home Instead, Jewish Care, amongst others.

We have also been working with a group of researchers from Lancaster University, and together we have submitted an application for National Institute of Health & Care Research funding to evaluate the impact and effect of palliative and end-of-life care volunteers in in-patient hospital settings.

Tips for others

- ***Who else can benefit from this work?***
In our opinion, all NHS Trusts would benefit from having a team of specialist 'end of life' volunteers to support patients, their visitors (relatives and friends), and ward staff - who do their best to care for their patients, but simply don't have the time to do this as they would like to.

We are working with acute and community trusts to help them set up teams of volunteers in a way that works for them. Our support is very flexible, and we work alongside local teams to create a service that works for their patients, staff, and community. The volunteers volunteer for their NHS Trust – not for the charity. The service 'belongs' to the NHS Trust – not to the charity.

Our aim is to inspire and empower others to provide the best possible support to people who are dying, whether they are in a hospital bed, a care home, a hospice or in their own home. We will work

with any individual or organisation to provide help and support for them to do this.

"I cannot thank you enough for your visits. I am so pleased my wife has more than just me with her for only a short time each day. I know it will happen sometime soon and I find it very hard to accept the inevitable. Your support has been invaluable. Keep up the excellent work."

Peter, whose wife received several visits from volunteers in her last days.

• **What advice would you give to others who want to do the same thing?**

Get in touch with The Anne Robson Trust! We can help set up a team of volunteers quickly and efficiently.

You will become part of a national movement to provide support to people who are dying in hospital, and will have access to the peer support groups and communities that we are creating.

Why re-invent the wheel?

A hand to hold. A listening ear. The presence of another person. These simple things become invaluable in the final days and hours of life.

Contact name: Liz Pryor.....

Contact email address: liz@annerobsontrust.org.uk.....

Date of innovation / initiative: Charity launched in May 2018.....

Do you have any attachments?

- "A picture is worth a thousand words". Are there any photos or graphics that could help bring your story to life?
- Include the End of Life Hospital Volunteer Leaflet.
- Include a visual of photos of volunteer teams...

If so, please upload them to the Fab site with this completed template.