Using volunteers to support end-of-life care

One trust established a volunteer support service to offer patients nearing the end of life, and their families, much-needed emotional support.

In this article...

- How volunteers can improve end-of-life care in hospital
- How the service was established and volunteers were trained
- Feedback on the service from volunteers, relatives and staff

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Abstract

The role of volunteers in end-of-life care in the acute hospital setting is not widely established. This article reports on an innovative model of care using trained volunteers that was introduced at a Liverpool trust in 2012. The volunteers were to provide a listening ear, comfort and support for patients who were dying, their families and friends. A training programme was developed and reviewed, with views from volunteers, staff and relatives evaluated. Psychological support for the volunteers was regularly provided.

Patients who are dying often experience loneliness, anxiety about impending death and depression (Claxton-Olfield et al, 2006), yet may have no or few family or friends to comfort them. Hospital remains the most common place of death (Department of Health 2008) and no one should die there alone, but palliative, emotional, spiritual, collaborative and interdepartmental care is needed to ensure this does not happen. Death and dying affects us all and improving end-of-life care is a national priority, as outlined in the DH’s (2008) end-of-life care strategy; this emphasised that improving end-of-life care in acute hospitals is crucial.

Key findings from the Office for National Statistics (2014) revealed that people dying from cancer at home or in a hospice were reported to have received better care than those who die in hospital. While the value of hospice volunteers in providing emotional support, companionship and friendship to patients and families at the end of life has been recognised (Burbeck et al, 2014; Claxton-Olfield et al, 2010), the role of volunteers in end-of-life care in the acute hospital setting is not widely established.

Training is the foundation for a strong and dedicated volunteer programme and appears to play an important role in the ability of volunteers to perceive themselves as being better prepared for when death occurs (Claxton-Olfield et al, 2006). However, studies reporting on training for volunteers working with people at end of life, again, focus on the hospice rather than the acute hospital (France et al, 2012).

In March 2011, the patient/carer representative of Cheshire and Merseyside Strategic Clinical Networks Palliative and End of Life Steering Group Network and the end-of-life/supportive care steering group at Aintree University Hospitals Foundation Trust (AUHFT) attended the OPCARE9 Conference in Liverpool – a European collaboration to optimise research for patients with cancer in the last days of life. One of the conference themes highlighted an Australian palliative care training scheme to educate volunteers in supporting patients at the end of life and their families, much-needed emotional support beneficial.
of life (State Government Victoria, 2007). These innovative ideas led the patient carer representative to consider introducing such a voluntary service in a trust in Liverpool.

**Aintree Volunteer Companionship Service**

Since 1997, the AUHFT volunteer scheme has been enhancing quality of life for patients, relatives and staff through the structured use of caring and supportive volunteers. However, volunteers were not involved in support towards the end of life.

The patient/carer representative proposed a volunteer companionship service in end-of-life care to the Cheshire and Merseyside Strategic Clinical Networks Education Sub Group and the trust’s end-of-life/supportive care steering group. This was met with enthusiasm and, as a result, a training programme was developed for the volunteers in line with support from both groups. In September 2011, a business case to fund the training programme was presented to Cheshire and Merseyside Strategic Clinical Networks Palliative and End of Life Steering Group and was successful.

**Setting up the service**

A monthly multiprofessional management group comprising a palliative care consultant, palliative care nurse specialist, patient/carer representative and volunteer manager was set up to review the compilation of the training programme and service. The volunteer manager approached 15 individuals from an existing cohort of volunteers who, as a result of their previous experience in critical care or accident and emergency environments, were considered able to cope with the sensitivities of a role in end-of-life care.

A role description was drawn up highlighting the care volunteers should give to patients and their families (Box 1).

**Training programme**

A two and a half-day interactive programme was drawn up, which covered:

- The principles of palliative care;
- Symptom control;
- Communication skills;
- Clinical governance;
- Spirituality.

The programme was developed with guidance from Cheshire and Merseyside Strategic Clinical Networks Education Sub Group in line with the key priorities in the DH’s (2008) end-of-life care strategy.

The training was crucial to the volunteer service’s success; it included theoretical and practical sessions and was facilitated by a multidisciplinary team.

**Volunteer training evaluation**

To assess the effectiveness of the training and how volunteers were coping with their new role, an audit was carried out to:

- Understand what worked well;
- Understand the challenges and how they were overcome;
- Identify important considerations for the continuation of the service.

The evaluations were undertaken at three intervals: before training, after training and three months into the companionship role. To facilitate this, volunteers met with their manager on a one-to-one basis to discuss their progress.

In general, volunteers agreed the training was effective in preparing them to support and comfort patients who were dying and their families. One volunteer said:

“After completing the course and training I feel confident in approaching patients and families and offering support.”

Suggestions for further training included:

- Helping relatives deal with their anger;
- Bereavement training or a counselling course;
- Refresher training after six months.

**The pilot scheme**

In May 2012 after the training programme was completed, a three-month pilot scheme was launched on five acute wards. The service was available five days a week between 8am and 8pm. Flyers announcing the new service were distributed to the wards.

Volunteers worked a four-hour rota and had a pager to inform them where support was required. All received a file containing:

- Telephone numbers of professionals providing support to the volunteers;
- Volunteers’ telephone numbers so they could contact each other when required;
- A poster advertising the service;
- Service record sheets;
- A reflective diary to record their experiences;
- The trust bereavement information booklet;
- *End of Life: The Facts* (Bit.ly/EndofLifeTheFacts), a booklet produced by Macmillan and Marie Curie Cancer Care to make the volunteers and families/carers aware of the services and support available at the end of life.

**Initial evaluation**

Four volunteers supported the first patient and family using the service. The support was recorded in the reflective diaries, which enabled them to capture their own feelings and thoughts as well as highlighting and discussing any issues requiring further support from the palliative care team and assistant clinical psychologist.

Regular support meetings with the volunteer manager and assistant clinical psychologist were held to encourage volunteers to relay their experiences. The assistant clinical psychologist shared various coping mechanisms with them and was available for one-to-one discussion if required.

After eight weeks of the service commencing, monthly evening sessions were introduced so volunteers could talk over any issues with the palliative care consultant and the clinical nurse specialist. The reflective diaries and peer support

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**BOX 1. VOLUNTEER ROLE DESCRIPTION**

The volunteer should work closely with the multidisciplinary team to give comfort and support to the patient, family or carer at their time of need by:

- Listening to their needs;
- Giving guidance and support by signposting them to the appropriate professional;
- Showing understanding and compassion appropriate to individual needs;
- Maintaining patient confidentiality at all times;
- Communicating concerns about the patient, family or carer to the ward nursing team;
- Ensuring that families and carers have access to refreshments and are aware of the facilities available to them;
- Exercising discretion when working in sensitive situations;
- Demonstrating an awareness of the role within the Volunteer Companionship Service and ensuring appropriate signposting to other members of the multidisciplinary team;
- Working as part of a team and accepting supervision and direction from the ward nursing team and the volunteer manager;
- Participating in regular review meetings, debriefing sessions with other volunteers and the volunteer manager as directed;
- Promoting the companionship service with designated wards;
- Participating in ongoing education activities relevant to the role.

The volunteer will be available to support patients, relatives and staff through the multidisciplinary team.

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<th>Item</th>
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<td>Listening to needs</td>
<td>The volunteer should be able to listen and understand the patient's needs.</td>
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<td>Giving guidance and support</td>
<td>The volunteer should be able to signpost to appropriate professionals.</td>
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<td>Communicating concerns</td>
<td>The volunteer should be able to communicate effectively with the team.</td>
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<td>Exercising discretion</td>
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<td>Demonstrating awareness</td>
<td>The volunteer should be able to demonstrate awareness of the role.</td>
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<td>Working as part of a team</td>
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Nursing Practice

Innovation

proved very beneficial, as one volunteer commented:
“Having our reflective diaries helped me a lot and also knowing that you have got support there in case of problems”.

As more volunteers completed the training, a mentorship programme was set up by the more-experienced volunteers offering a shadowing programme and one-to-one support to settle new volunteers into the role.

Staff feedback
The deputy director of nursing facilitated feedback sessions with senior nurses of the five pilot wards to seek their views of the service. Comments included:
“At first it was thought that it may be difficult for the patient and their relatives to build another relationship at this stressful time. However, once introduced, the service was deemed great as volunteers sit and talk with patients and family, and provide psychological support for them.”  (Sister 1)

“I find it very useful when a patient has nobody.” (Sister 2)

“Just them being there really works and it is a great bonus.” (Sister 3)

In the feedback session some areas for development were identified; comments included:
“Need more marketing, perhaps volunteers could have business cards.” (Sister 2)

“It would be great if volunteer companions covered a weekend.” (Sister 4)

“We should give the volunteers the opportunity to complete an NVQ in end of life care.” (Sister 1)

Volunteer feedback
A few of the volunteers reported initial concerns about the introduction of the service:
“I wish the ward staff were more accommodating.” (Volunteer 1)

“A small number of staff were unsure of the volunteer role.” (Volunteer 2)

“The end-of-life programme is great. We need a better system to let us know what wards need us and to let us know where the patients are.” (Volunteer 3)

As a result of the above feedback, clarity of the volunteer role and communication channels were discussed with senior nurses. The volunteer manager also attended divisional meetings and visited wards regularly to help improve communication and awareness of the service. Despite initial concerns, however, the volunteers were enthusiastic and motivated.

Relatives’ feedback
The relatives who used the service gave positive feedback:
“We, as a family, think it’s an excellent service you provide to families when really needed.” (Relative 1)

“This is an excellent service for families, can’t thank you enough. Keep up the good work.” (Relative 2)

When asked what was the single most important thing the volunteers did for them, they said:
“To be there.” (Relative 1)

“It helped me to know that if Mum had no visitors, a volunteer could sit with her until her visitors came.” (Relative 2)

“They were present. It was just enough to know someone else was there.” (Relative 3)

A section of a letter received from the daughter of the first patient supported by the volunteers also showed how much they were appreciated:
“I had some wonderful people from the volunteers sit with both myself and Dad. I hope that you’re encouraged to carry on with it as I think it is something that is very much needed. The volunteers were our guardian angels that day.”

Service promotion
Awareness of the service was improved by coverage on Radio Merseyside. Over a five-day period before Dying Matters week in 2013, individual interviews with those involved in the service were broadcast.
Promotion led other acute hospitals and hospices to express an interest in setting up a similar service. Visits to the hospital were arranged and details of the training programme shared. In January 2013 a delegation from the Cabinet Office and members of Nesta, an innovation charity with a mission to help people and organisations bring ideas to life, visited the trust. The visit was a success in that they felt the service was transferable across other acute trusts.

Developments to date
To date, six training programmes have been completed, which enabled the volunteer companionship service to go trust wide in 2013. Recruitment is underway for a seventh cohort.

By February 2016, volunteer companions had responded to 378 requests for patient support. Awareness of the services is continuing to spread nationwide with more requests for information about the training programme.

Conclusion
The introduction of this service has revealed that volunteers can make a substantial contribution to meet the needs of people who are dying and their families. However, training alone for end-of-life care is not sufficient; volunteers need to know there is close support with regular supervision as well as psychological and peer support.

Our volunteers feel it is a privilege and an honour to be given the opportunity to contribute to the support of patients and families at end of life and felt that the training and support they received allowed them to carry out their role with competence and confidence. The selection, initial orientation and ongoing management of volunteers may be time consuming and sometimes difficult but it is helpful to reflect on the fact that when medicine can do no more, a smile, a touch and a friend are the best prescription – this is what our volunteers have in abundance.

References

For more on this topic go online...

Taking oral histories to improve end-of-life care
bit.ly/NToralHistories