The Role of Volunteers in End of Life Care

Sharon Bird

People's Voice, North West Coast Clinical Network and Patient Carer Representative, Aintree University Hospital Trust

Kath Davies

Clinical Network Coordinator, North West Coast Clinical Network

Introduction

- Value of volunteers
- Role of volunteers
- Role of staff members
- Expectations and responsibilities
- Training
- Support
- Counselling

Bird et al (2016) Using volunteers to support end of life care Nursing Times 112,14,12-14
End of life could be on any ward really: L. J. Brighton, J. Koffman, V. Robinson Palliative 2017 Journals Sage pub.com
A Qualitative study of hospital volunteers end of life care training needs and learning preferences.
The use of reflective diaries in EoL training programme. A study exploring the impact of self-reflection on the participants in a volunteer training programme. Alison Germaine, Kate Nolan, Rita Doyle, Stephen Mason, Maureen Gamble. BMC Palliative Care 15 (1) 28 2016

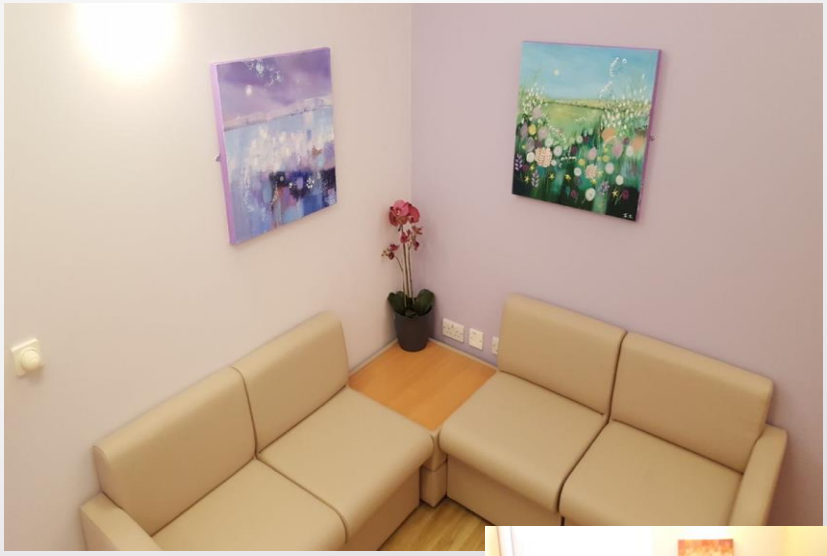
My story

- Nursing career
- Death of a loved one – hearing bad news
- Desire to improve experience for others
- Joined specialist palliative care development unit
- Relative's rooms
- Opcare Conference 2011
- Invitation to join Cancer Network People's Voice
- Joined Education Sub Group

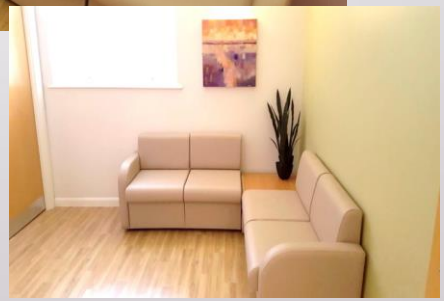
Relative's Rooms at Aintree

Safe haven: transforming relatives' rooms

Before



After



Bird et al (2011) Safe Haven Transforming Relatives' Rooms Nursing Times; 107; 5, 16-18

Opcare Conference - 2011

- Opcare 9 End of Life Conference in Liverpool
- Australian volunteer training programme to sit with EoL patients
- Support from Network Education Sub Group
- Business case to fund the volunteer companionship service

Aintree's Volunteer Companionship Service

- 700 volunteers in 40 different roles
- 3-day training programme
- 3 Month Pilot Scheme
- Following successful pilot now operating Trust-wide 7 days a week
- Model used in other Trusts
- Parliamentary and Helpforce Awards

[redacted]

Volunteer Services in Cheshire & Merseyside

Queenscourt Hospice, Southport

Hospice at Home and Inpatient Volunteers

"…She (the volunteer) really did make a difference. This patient was particularly anxious and the volunteer helped to ease her anxiety …"

"It was such a comfort knowing my mum was not on her own and someone was sat with her when I was not able to. "

Hospice of the Good Shepherd, West Cheshire Bereavement Volunteers

"…. Volunteers are helping to change our culture and attitude to palliative care"

People's Voice

Achievements

- Network's strategic groups
- Formed a new charity
- Volunteering for SPC Units at Liverpool University Hospital
- Macular Degeneration and Liver Trust
- Local patient participation groups
- Links to Innovation Agency
- NICE accreditation - Audit

Awards

- BMJ Award 2018 Finalist – Patient Partnership Bereavement Specification
- AbbVie Sustainable Healthcare Award Nomination – Making Health and Social Care Patient Friendly
- North West Coast Research and Innovation Awards 2019 Nomination - Outstanding Contribution to Patient and Public Involvement in Research
- Liverpool Hope University and Leaders Club Winner – 'Common Good' category

Member's Stories

Allan

- Cared for his wife, who had Alzheimer's disease, for 7 years.
- Volunteered for Alzheimer's Society Wirral.
- Volunteered for People's Voice Dementia group and later joined the Palliative and End of Life Care group.
- Form a new charity in August 2018 to support people with dementia and their carers - Dementia Together Wirral

Bob

- Volunteer in the Palliative Care inpatient unit at Royal Liverpool Hospital.
- Represented Peoples Voice in London accepting the finalist certificate of AbbVie's Sustainable Healthcare Awards.
- He was invited to summarise his thoughts, as a lay person, at a Shared Decision Making in End of Life Care Conference.
- Member of the Liver Trust, holding a regular educational stall at Royal Liverpool
- A Peoples Voice representative in Diabetes, Syringe drivers, Ascites, Fatigue, and Substance Misuse audit guidelines.

Both Allan and Bob, along with other People's Voice members have taken part in Dying Matters events at Liverpool Museum

Dementia Together Wirral

Dementia Together Wirral

Social Support and Friendship

NOVEMBER 2019

ONGOING CALENDAR

DEMENTIA FRIENDLY EVENTS

Calendar is available online at

www.dementiatogetherwirral.org

www.deepcww.org

DAA Dementia Action Alliance

deep Cheshire West and Wirral

Dementia Friendly

Next DEEP Wirral meeting is Tuesday 5 November 2019 at 11am
St Barnabas Village Centre, Bromborough, all are welcome.

Dementia Together Wirral

Social Support and Friendship

Memory Cafés 2020

Friendship, reminiscence, games, learning, pictures, interaction in an understanding environment for those with or without diagnosis of dementia, their carers and ex-carers as offered by Dementia Together Wirral volunteers

First Monday of month 10am to 12 noon **Coffee Aroma** 4-6 Brunswick Court Price Street Birkenhead CH41 6LW	**First Wednesday of month** 10am to 12 noon **Sun Lounge Café** Port Sunlight Garden Centre Port Sunlight Wirral CH62 5DY
Second Tuesday in month 10am to 12 noon **Hoylake Cottage (Sandhills)** Birkenhead Road Hoylake Wirral CH47 5AQ	**Second Wednesday in month** 10am to 12 noon **[illegible] Coffee Shop** Station Road [illegible] Wirral CH61 6HN
Third Tuesday in month 11am to 1pm **Floral Pavilion** Marine Promenade New Brighton Wirral CH45 2JS	**Last Tuesday in month** 10am to 12 noon **Atrium Restaurant** [illegible] Farm Garden Centre Birkenhead Road [illegible] Wirral CH47 9RE
Last Wednesday in month 3pm to 5pm **The Blue Bicycle** 10 The Cross Neston Cheshire CH64 9UB	**Last Friday in month** 1pm to 3pm **142 Coffee Lounge** The [illegible] 142 [illegible] Road Birkenhead CH41 6EY

Visit our website as more memory cafés are coming on the Wirral peninsular during 2020

DAA Dementia Action Alliance

deep Cheshire West and Wirral

Dementia Friendly

Bereavement Specification

- Hospital Transform Group
- Focus Group
- Table top exercise
- Review all bereavement information in C&M
- Developed minimum and gold standard Bereavement Specification
- What to Expect
- Bereavement Literature leaflet

Bereavement Specification

Guidance to support bereavement care in Acute Hospitals

NHS
Cheshire and Merseyside
Palliative and End Of Life Care Network

The Cheshire and Merseyside Palliative and End of Life Care Network has produced this guidance for Acute Hospitals in developing appropriate bereavement services. The Network commissioned a survey to seek the experience of bereaved relatives. The survey "Care of the Dying Evaluation (CODE)", published in 2015, showed wide variation in the availability of support, information and facilities for families and carers of those dying in the hospital setting.

Despite a national drive to support more patients to die in their own home, in reality the majority will spend their final weeks, days and hours of life in a hospital setting. A few may express a preference to remain in hospital at the end of their life but for the majority, dying in hospital comes at the end of a period of acute illness and, sometimes intensive, treatment. At times, delays in discharge processes or a scarcity of resources to provide care in the place of their choosing means that dying in hospital is an undesired inevitability. Subsequently, it is often a time of great uncertainty, emotion and fear for many families and carers and we, therefore, have an essential duty to provide timely, proactive information, facilities and support, and ensure our bereavement processes make this period of transition and distress as smooth as possible.

The Network Transforming End of Life Care in Acute Hospitals Group and the People's Voice Group worked closely together to produce guidance, ensuring the views of bereaved relatives were at its core.

A bereaved relatives survey was undertaken to explore both positive and negative experiences of losing a loved one in hospital. Trust websites and information leaflets were examined and, following this, a workshop was held to discuss the main themes and resources that carers felt would improve or enhance the services available, and additionally a small subgroup undertook a more detailed project to outline the gold standard requirements for mortuary visiting facilities.

Timely access to information and resources is essential and many bereaved relatives expressed the wish that staff had been more proactive in exploring end of life and bereavement wishes, and been offered information prior to death to help them better prepare. This guidance should, therefore, be read in conjunction with 'What to expect when somebody close to you dies' (WTE1) and Bereavement Leaflet Recommendations (BL1), two further joint pieces of work undertaken by the two network groups, which give guidance on the information needs of patients and carers in the days before death and into early bereavement.

Given the challenges faced, we recognise that developing an exemplary bereavement service is an aspiration that will take time to realise. However, there are many aspects of services that the project group considered essential in providing an appropriate level of bereavement information and support. We have, therefore, developed a dual standard – a minimum standard that all hospitals should ensure is in place, and a gold standard of service, which should form part of the longer term end of life strategy for the Trust.

We hope you will find this guidance of value in developing and evaluating your services.

Dr Julie Raj Sharon Bird

On behalf of the
Transform Acute Hospitals and People's Voice groups of the
Cheshire and Merseyside Palliative and End of Life Care Network

B1

https://www.england.nhs.uk/north-west/north-west-coast-strategic-clinical-networks/our-networks/palliative-and-end-of-life-care/end-of-life-resources/bereavement-service-improvement-resources/

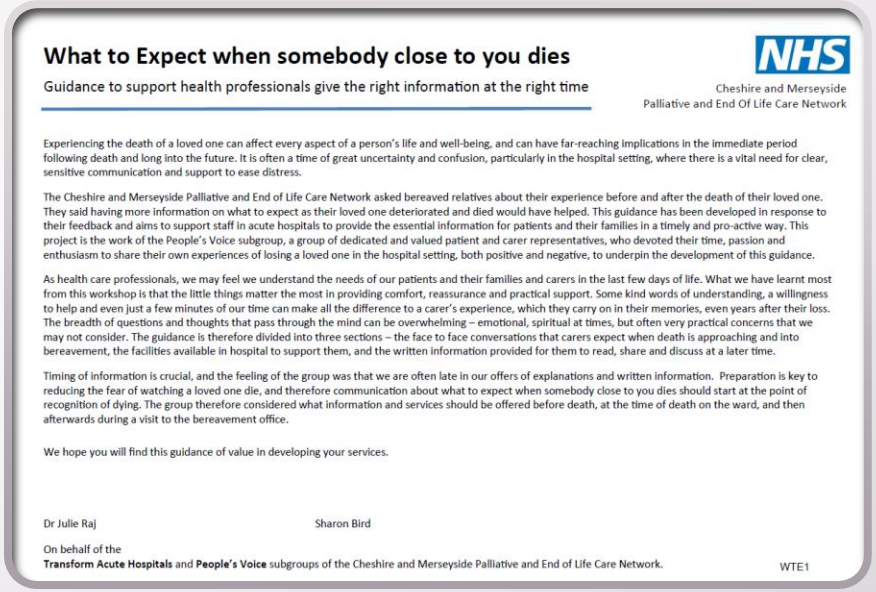
'What to Expect' when somebody close to you dies

3 aspects of carers' needs reviewed:

- Face to face discussion
- Written information – for wider family and to refer back to
- Facilities

3 clear time frames when support is required:

- as death approaches
- at the time of death
- afterwards



What to Expect when somebody close to you dies

Guidance to support health professionals give the right information at the right time

NHS
Cheshire and Merseyside
Palliative and End Of Life Care Network

Experiencing the death of a loved one can affect every aspect of a person's life and well-being, and can have far-reaching implications in the immediate period following death and long into the future. It is often a time of great uncertainty and confusion, particularly in the hospital setting, where there is a vital need for clear, sensitive communication and support to ease distress.

The Cheshire and Merseyside Palliative and End of Life Care Network asked bereaved relatives about their experience before and after the death of their loved one. They said having more information on what to expect as their loved one deteriorated and died would have helped. This guidance has been developed in response to their feedback and aims to support staff in acute hospitals to provide the essential information for patients and their families in a timely and pro-active way. This project is the work of the People's Voice subgroup, a group of dedicated and valued patient and carer representatives, who devoted their time, passion and enthusiasm to share their own experiences of losing a loved one in the hospital setting, both positive and negative, to underpin the development of this guidance.

As health care professionals, we may feel we understand the needs of our patients and their families and carers in the last few days of life. What we have learnt most from this workshop is that the little things matter the most in providing comfort, reassurance and practical support. Some kind words of understanding, a willingness to help and even just a few minutes of our time can make all the difference to a carer's experience, which they carry on in their memories, even years after their loss. The breadth of questions and thoughts that pass through the mind can be overwhelming – emotional, spiritual at times, but often very practical concerns that we may not consider. The guidance is therefore divided into three sections – the face to face conversations that carers expect when death is approaching and into bereavement, the facilities available in hospital to support them, and the written information provided for them to read, share and discuss at a later time.

Timing of information is crucial, and the feeling of the group was that we are often late in our offers of explanations and written information. Preparation is key to reducing the fear of watching a loved one die, and therefore communication about what to expect when somebody close to you dies should start at the point of recognition of dying. The group therefore considered what information and services should be offered before death, at the time of death on the ward, and then afterwards during a visit to the bereavement office.

We hope you will find this guidance of value in developing your services.

Dr Julie Raj Sharon Bird

On behalf of the
Transform Acute Hospitals and **People's Voice** subgroups of the Cheshire and Merseyside Palliative and End of Life Care Network.

WTE1

Bereavement Literature

- People's Voice literature review
- Agreed a minimum standard for bereavement literature
- Before death, at death, after death

NHS

Bereavement Literature in the Trust setting

Guidance to reviewing literature that supports bereavement care in Acute Hospitals

We hope you will find this guidance of value in developing your services.

Dr Julie Raj
Chair

Sharon Bird
Chair

On behalf of the
Transform Acute Hospitals and **People's Voice** groups of the Cheshire and Merseyside Palliative and End of Life Care Network.

BL1

Audit results

Eight out of eleven CCG areas in Cheshire & Merseyside responded

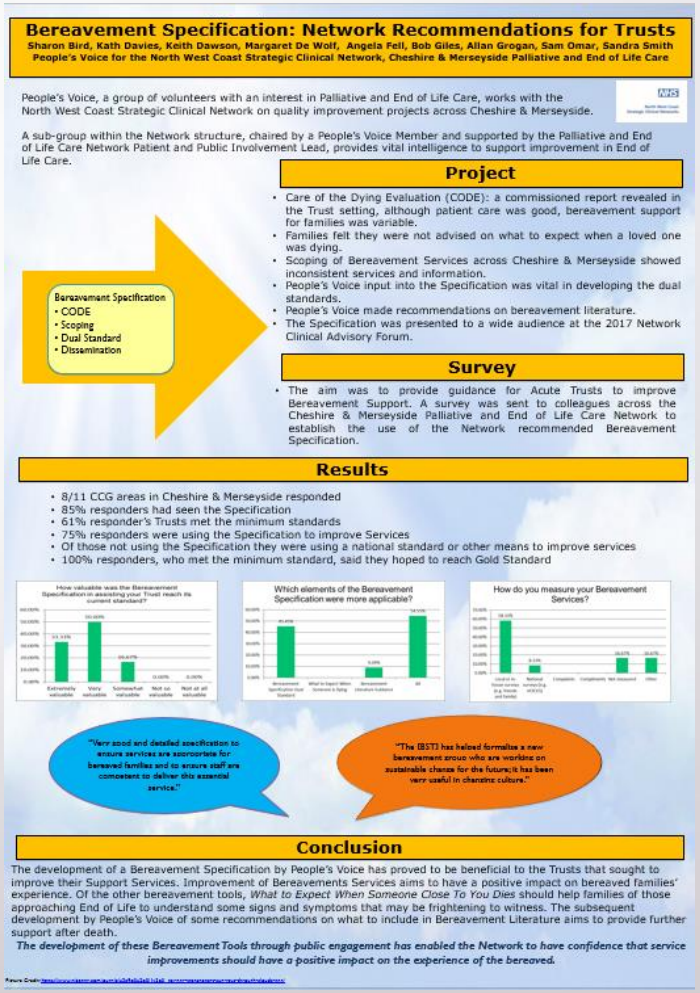
85% of responders had seen the Bereavement Specification

61% of responder's Trusts met the minimum standard

75% of responders were using the Specification to improve services

Of those not using the Specification they were using a national standard or other means to improve services

100% of responders who met the minimum standard said they would aspire to reach Gold Standard



Bereavement Specification: Network Recommendations for Trusts

Sharon Bird, Kath Davies, Keith Dawson, Margaret De Wolf, Angela Fell, Bob Giles, Allan Grogan, Sam Omar, Sandra Smith
People's Voice for the North West Coast Strategic Clinical Network, Cheshire & Merseyside Palliative and End of Life Care

People's Voice, a group of volunteers with an interest in Palliative and End of Life Care, works with the North West Coast Strategic Clinical Network on quality improvement projects across Cheshire & Merseyside.

A sub-group within the Network structure, chaired by a People's Voice Member and supported by the Palliative and End of Life Care Network Patient and Public Involvement Lead, provides vital intelligence to support improvement in End of Life Care.

Bereavement Specification
- CODE
- Scoping
- Dual Standard
- Dissemination

Project

- Care of the Dying Evaluation (CODE): a commissioned report revealed in the Trust setting, although patient care was good, bereavement support for families was variable.
- Families felt they were not advised on what to expect when a loved one was dying.
- Scoping of Bereavement Services across Cheshire & Merseyside showed inconsistent services and information.
- People's Voice input into the Specification was vital in developing the dual standards.
- People's Voice made recommendations on bereavement literature.
- The Specification was presented to a wide audience at the 2017 Network Clinical Advisory Forum.

Survey

- The aim was to provide guidance for Acute Trusts to improve Bereavement Support. A survey was sent to colleagues across the Cheshire & Merseyside Palliative and End of Life Care Network to establish the use of the Network recommended Bereavement Specification.

Results

- 8/11 CCG areas in Cheshire & Merseyside responded
- 85% responders had seen the Specification
- 61% responder's Trusts met the minimum standards
- 75% responders were using the Specification to improve Services
- Of those not using the Specification they were using a national standard or other means to improve services
- 100% responders, who met the minimum standard, said they hoped to reach Gold Standard

How valuable was the Bereavement Specification in assisting your Trust reach its current standard?

Which elements of the Bereavement Specification were more applicable?

How do you measure your Bereavement Services?

"Very good and detailed specification to ensure services are appropriate for bereaved families and to ensure staff are competent to deliver this essential service."

"The (BST) has helped formalise a new bereavement group who are working on sustainable change for the future; it has been very useful in changing culture."

Conclusion

The development of a Bereavement Specification by People's Voice has proved to be beneficial to the Trusts that sought to improve their Support Services. Improvement of Bereavements Services aims to have a positive impact on bereaved families' experience. Of the other bereavement tools, *What to Expect When Someone Close To You Dies* should help families of those approaching End of Life to understand some signs and symptoms that may be frightening to witness. The subsequent development by People's Voice of some recommendations on what to include in Bereavement Literature aims to provide further support after death.

The development of these Bereavement Tools through public engagement has enabled the Network to have confidence that service improvements should have a positive impact on the experience of the bereaved.

Mortuary Refurbishment at Aintree

- **Reception photos**

Before

After

Mortuary Refurbishment at Aintree

I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel

'Maya Angelou'

The Way Forward

- Advance Care Planning - bespoke training for volunteers
- Review procedure for Companionship Service
- Spreading the word of the value of volunteers

Conclusion

- People's Voice
- Network Support
- Continuing role of volunteers

Contact Details:
Kathryn.davies16@nhs.net
lyndabird1946@gmail.com