VALE Service

Volunteers At Life's End

Evaluation of the Pilot of a New LOROS Service in Care Homes

LOROS
Hospice Care for Leicester, Leicestershire & Rutland

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A personal note

Whilst writing this evaluation my own father as been dying, slowly, in a care home. There have been times that he clearly wanted me to stay and keep him company. He would have valued a quiet companion; just someone there. It has impressed on me the value of such a service and how neither care homes nor most families can provide this themselves. I believe that LOROS has an important role in developing and providing this as part of its leadership in the provision of excellent end of life care for all.

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Executive Summary

The VALE pilot service development recruited nine volunteers and four care homes to explore the benefits and challenges of LOROS trained volunteers providing support in the last days of life to those care home residents with no, or few, family visitors.

The culture and end of life care activity of the four care homes was diverse. Two were motivated to engage in the project because they had a strong focus on end of life care and wanted to develop this further with LOROS, two wanted to develop this as more of a focus within the care home. Considerable positive comment about LOROS from the four care home Matrons clearly underpinned their willingness to be involved in the pilot. Indeed other homes that have had preliminary discussions about the service held similar views. Thus the VALE service being developed and provided by LOROS appeared to open doors for residents to have this companionship and support.

Of the nine volunteers the majority had a nursing background and were keen to develop a role in an area they had found very satisfying in their professional life. Those without a health care background were motivated for this new volunteering role by a general sense of valuing the importance of this time in life and of being able to support people who might otherwise be alone.

The three day training programme largely met the needs of the volunteers although those who did not have a health care background would have welcomed more observation of and learning around about the process of dying and what to expect.

Residents and families were largely supportive of the development although some needed reassurance that it was an additional and not a substitution service. Matrons were apparently able to discuss the service with families with little difficulty. Although the LOROS label to the VALE service was not explicitly commented on, it was inferred that this made the focus of the care from VALE easy to understand and also provided reassurance to families as to the quality of the service. Introducing the service on admission or even on enquiry was acceptable but not a time when decisions about using it could be realistically made. The VALE leaflet was found to be an important tool for the service.

Three of the nine volunteers worked with seven residents in the 8 months of this evaluation. All of these residents had family and for all but one the family was visiting as well as the volunteer. Two volunteers gave direct support to a family member whilst they were sitting with a resident. None of the residents died when a volunteer was with them. Care homes made request for VALE support for a further five residents. Some of these residents died within hours, before a volunteer could get there, and some died over the next few days but a volunteer had not been available.

Care home staff were open to the development but initially somewhat apprehensive about the new role and whether volunteers would fit in with their teams and how they would cope with sitting with dying residents. However, in homes where residents had used VALE there had been a rapid increased confidence in the service and acceptance of volunteers as a valuable part of the team.

In care homes where residents had used VALE the service had undoubtedly added value to the care home. As far as can be inferred from the comments of staff and volunteers, VALE was also valued by and made a difference to residents and their families.

There are a numbers of obstacles in developing a VALE service for care homes. Firstly the number of residents likely to require the service in any one care home is very low. This might be around 1 in 4 of residents who die. Even in a care home with 50 deaths a year (a high number) this would then be one resident a month on average. Secondly the need for VALE is fairly immediate and intense, requiring a very responsive service.

Considerable reflection, mainly from volunteers, was given to the potential issues, for both resident and volunteer, of a stranger being present alongside a dying resident. In addition, thought went to the possible emotional, impacts, both on the volunteer and for the VALE service, of forging earlier relationships with residents. Dying has an unpredictable time course and although VALE is not a befriending service it would seem that it’s main value and perhaps the satisfaction of the volunteers, is in being with people who need company in the last weeks of that journey.

VALE appears to work best where volunteers maintain regular contact with care homes by phone. When a resident is identified by the care home as needing the service there is some indication that volunteers organizing a visiting schedule between themselves is helpful to care homes. Given the evidence of levels of need it would seem that a viable, responsive service could only be maintained by a pool of volunteers working across a group of care homes with robust systems for both regular contact with care homes and coordination of response to individual resident needs. The experiences explored in this evaluation suggest that the criteria for referral to VALE should not be restricted to the last hours of life, nor to aim for residents to have VALE at the point of death but aim for VALE to provide companionship and support quality of life in the last few weeks and days. VALE is also likely to be needed alongside family visitors and on occasion volunteers may have a very important role in their interaction and support of family.

Contents

1. Introduction

"As people come close to death, what they want and need becomes very simple. They want that most underused of human resources — the gift of attention. At the moment of death, all that matters is what is most essential in us and most simple to give. The dying need our humanity. Participating in the death of another human being, although heartbreaking, is a privilege that is unforgettable, inexpressible, and beautifully real."
From *The Grace in Dying* by KD Singh 2000

"No one should die alone……. Each human should die with the sight of a loving face."
Mother Teresa of Calcutta

There is understandably an absence of research informing us about what patients say they need in the last hours of life. As a proxy for the patient the views and experiences of family and staff are used to inform services and the content of care. Undoubtedly one of the strongest views is that the dying person should be comfortable as possible. These concerns about comfort are multidimensional: physical, psychological, social and spiritual. The presence of someone with the dying person goes someway to providing and ensuring elements of this comfort: by addressing basic care needs through sips of water and safety; by helping to reduce fear through touch and soothing sounds; and most particularly perhaps reducing a sense of aloneness. Staff are often regretful if patients die alone and relatives are often distressed and angry. However we also know that not unusually patients appear to 'choose' a solitary moment to die. Finally stopping breathing when those that have been with them for long periods at the bedside, just 'pop-out' for a short break.

Two programmes in America have influenced the thinking at LOROS to develop a new type of service to support people in the last hours of their lives. *No One Dies Alone*[1] *(NODA),* a hospital volunteer service was developed at Sacred Heart Medical Centre in Oregon in 2001 in response to a nurse's experience of not meeting the needs for a comforting presence of dying patients. '*Can you stay with me?*' was a clear request from many patients who either had no family or whose family were not available and NODA's philosophy is to provide human companionship in the last hours of life. *Sacred Dying*[2] a volunteer vigiling programme develop by Megory Anderson in California is concerned with bringing spirituality, through presence and ritual, into the physical act of dying. Sacred Dying facilitates the creation of a setting where death is experienced with honor, respect, and sacredness.

LOROS's vision was to develop a service that provided appropriate companionship to people dying in care homes. The principles of the service development were:

- It would be provided by volunteers who were already part of LOROS' volunteer team.
- The service would provide companionship to socially isolated people who were identified as (probably) being in the very last stages of their lives.
- Volunteers would be trained specifically for the new role.

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[1] http://www.peacehealth.org/shared-pages/Pages/_no-one-dies-alone-

[2] http://www.sacreddying.org

The new service required a team of people to develop it. This report provides an evaluation of the service from a range of perspectives. The intention of the evaluation was to

- Understand what worked well and why
- Understand the challenges and how they were overcome
- Assess the added value of the service for dying people in care homes
- Identify important considerations for the continuance of the service

2. The Volunteers

Nine volunteers were recruited for the pilot of VALE one of whom was male. All were already volunteers with LOROS. One was under 50, four were between 50 and 65 years old and four were over 65 years old. Seven had been with someone as they had died but two had not. Five had a background in nursing.

2.1 The background and motivation of volunteers

A very strong sense of self-fulfillment and purpose was evident for some volunteers:

- *Thank you for giving me the opportunity. I have been thinking for some time that something was missing in my life. … Thank you for letting me take part in this great journey. I hope I can make a little difference for someone at the end of their life.*

- *This gives me some reason to be a good human being. I would like to give something back of myself in helping someone who has no one near them before they die.*

Some volunteers had been nurses and were comfortable being with very sick people. Their nursing vocation was evident in their enjoyment and sense of fulfillment in being with people as they died.

- *I'm glad I decided to do this, a feeling of contentment to get back into what I enjoyed doing so much.*
- *I want to give something back to the NHS*
- *I have witnessed some not very happy deaths and feel that things should be made better for patients and family*

A sense of a restoring the brokenness of human relationships in society was clear in some volunteers thinking.

" *There are millions of people in the world- yet we live in our own world and sometimes never know the name of our neighbours…… No one should have nobody.*"

The volunteers spoke of their own personal experiences of the family members deaths and reflected on the circumstances. Some of these family members had been alone and this left lasting regret and sadness motivating volunteering for this new service.

Others were in part motivated by their own thinking about death.

- *Death and dying has always been an interest, having studied this in university. I think about death daily and feel comfortable with it. I'm hoping that I can provide and share some of this comfort with others who express a need at the end of their life.*
- *As I get older am increasingly aware of my own mortality. I would want someone to provide this human contact and re-assurance for me when the time comes.*

Some were already working as volunteers on the LOROS ward and others with LOROS family support services and wanted to build on this role.

- *I love my job at LOROS before I 'retired' and then started with family support services. It has been a very gratifying and humble time with the 'friends' I have made during visits with my families.*
- *Although working with different people, it is a natural progression from work with FSS. It is an area in which I feel able to participate which is probably not too common as people usually avoid death.*

As spiritual support and 'witnessing' the passing from life to death is one aspect of care of people that are dying volunteers were asked to describe their spiritual beliefs. This aspect of themselves was not apparently an overt motivator for the role but underpinned their life values and their wish to make a difference in caring for others.

- *Strong, though not rigid and definitely not judgmental.*
- *I am a supporter of kindness and compassion, and seizing the moment to make a little positive difference to another. Given a subtle gesture makes a huge difference.*
- *I am a very religious and caring person I put others before myself.*
- *As a roman catholic I do have a very strong faith but appreciate that we live in a multi faith society and therefore respect and acknowledge other health beliefs and will do my best to what ever the patient wants for a peaceful death.*
- *Lapsed Christian trying to believe*
- *Open, caring and non-judgmental*
- *Christian*
- *In terms of religion – thin. Generally accepting of what makes people tick, we are all individuals with many varied sets of beliefs*
- *As a regular church goer I believe in a 'life after death' although could not explain how I perceive that to be.*

3. The Care Homes

Four care homes were approached and agreed to participate in the pilot. Two of the care homes came forward through discussions with EMCARE (the East Midlands Care Association) and two were approached directly by Dr Faull. The purposive sampling of care homes was intended to include both residential and nursing, care homes in both Leicester City and Leicestershire County, owner managed and larger group ownership care homes (table 1).

Table 1. Details about the four care homes

	Residential	Nursing	County	City	Beds	Owner manager	Deaths in 12 month

							period
Nightingales	√	√	√	x	37	√	50+
Hunters Lodge	√	x	√	x	36	√	4
Cedar Court	√	√	√	x	43	x	18
Langdale View	√	√	x	√	34	x	18

3.1 Hunters lodge

The care home runs with 98% occupancy with a largely white British clientele representative of its rural North East Leicestershire location. There are 41 staff of whom 2 are registered nurses. Residents stay for many months and there are about 3-4admissions a year with the same number of deaths. Only one resident has not died in their care home in the past four years. The home has a strong interest in providing excellent end of life care. It is accredited and was awarded *Beacon Status* for the Gold Standards Framework and all the residents are on the palliative care register. The care home is supported by one GP practice and a single team of community nurses.

3.2 Langdale View

Langdale View is one of four care homes in the Langdales group in Derbyshire and Leicestershire. Langdale View is situated in Leicester city providing mostly nursing care to residents from a diversity of ethnic backgrounds although 70% are white British. There are 25-30 staff four of whom are registered nurses supplemented by two bank nurses and the Matron. There are over 45 admissions a year with 3 or more deaths a month recently as they had been able to accept more patients being discharged from hospital specifically for end of life care. Very few of the residents who die do not do so in the care home and 60% of residents had no families. Residents at the care home are registered with one of five GP practices. The care home has found that GPs are unwilling to take on too many patients too frequently who are dying and request that that ‘work load’ be spread around.

3.3 Cedar Court

Cedar Court is one of 240 homes in its National group. It serves a predominantly white British community in South Leicestershire providing mostly nursing care. There are 50 staff of whom 9 are registered nurses. Staff are originate from 14 countries. There are 1-2 deaths a month and in the last year only one resident died in hospital rather than the care home. Patients are mostly registered with four GP practices.
The Matron of this care changed between in October.

3.4 Nightingales

The family run care home runs with >95% occupancy and provides predominantly nursing care to residents from a diversity of countries with predominantly Christian backgrounds in South Leicestershire. There are 45 staff of whom 8 are registered nurses. The care home is very committed to providing excellent end of life care and has at least 4 deaths a month. The care home is accredited for the Gold Standards Framework and works with four GP practices. Two of the 33 residents who died in the first six months of 2012 did not die in the care home, both dying at LOROS.

3.5 The motivation of care homes

The reasons why the four care homes engaged in the pilot were understandably individual. Whilst some saw it as helping the home develop this area of practice (end of life care) in which they perceived gaps and needed support from people with specific skills and training backed by LOROS, others were very confident in this and saw it as an opportunity to provide support for patients without carers.

All were motivated by a commitment to providing good end of life care.
" I feel passionate about the care of residents coming to their last days. I feel anything that can enhance a good death and experience for those left behind can only promote better understanding and care"

"The experience of the family left behind. That's an important thing for us. I think it's still a taboo subject and if we can promote understanding and better care, then the next time they come across this in their family they may not be so worried."

"We have residents who do not have relatives or their relatives distance from us. When people come to the last stages of their life it is not just their medical conditions that need addressing, yes pain and distress are important but anxiety can lead to these symptoms. All of us need to know there is someone for us, someone to offer a smile, a hand to hold; someone to sit with us so we are not alone."

Some care home matrons had strong personal as well as professional reasons for excellence in end of life care and the experience of relatives being a strong focus of their work. For some their faith also influenced this and the importance of people not dying alone. The personal experiences of other care home staff were also mentioned as motivators for the care home by the matrons.

Working with LOROS was seen as an opportunity to access a high level of experience and expert training. A hospice is seen as providing a model of excellence in care at the end of life which would guide and support care in the care home.

The 'second' Matron of Cedar Court during this pilot had had experience at her previous care home with a similar service in Derby which was available at night and which she had found very useful in supporting the care for residents.

3.6 Care home thinking about what VALE would do

In addition to views expressed during one to one interviews with the four care home matrons some staff in care homes responded to a questionnaire survey at the beginning of the project which asked them about how they envisioned the service.

3.6.1 How do you think VALE will work with you?

- Come and tell staff if there are any changes or the resident appears to be uncomfortable or in pain
- Ask us to tell them about the residents likes and dislikes and how their situation is
- Communicate well.
- Pass on any information they think we may need whilst we are not with them.
- Be pleasant at all times and let us know of any concerns that they may have
- A valued member of the team as we all rely on each other

3.6.2 What are your hopes of VALE for residents and families?

- It will provide extra care and one to one time for residents at the end of life. This isn't always possible for the carers.

- Extra comfort
- Provide residents with a source of peace of mind and comfort
- To give our residents the chance to talk to someone on a one to one basis that is not care home staff.
- Most beneficial to those with few visitors regularly.
- Knowing that others out there care and want to spend time with them and listen
- The feeling that people care.
- An individual who will be able to spend time on just them so they keep their own identity.
- A sense of security. They may feel it is supporting their family too.
- That residents don't die alone.
- Reassure residents that they are not alone, also relatives who have work commitments.
- To offer comfort and support either to relatives and the person in end of life care.
- May help families being able to leave without feeling guilty.

3.6.3 What are your hopes of VALE for the care home?

- That residents are not alone whilst staff are busy. Staff sometimes feel guilty at not having time to sit with residents especially if they have no family.
- Hopefully it should spread the load of end of life care so that carers can do their job better.
- Spread the load especially when someone requires one to one time.
- Ease pressure on staff knowing that there is someone in their presence.
- To ease the work load slightly
- Providing their experience and knowledge
- Freeing us at times when we are needed elsewhere, knowing that we have not to leave the person on their own
- To have more time to spend with others
- A learning experience, exchange of knowledge, sharing good practice
- Will help staff feel secure that someone will be with the resident so they will feel less guilty when they can't because of competing needs of other residents.
- Maybe we can learn something because volunteers who are trained at LOROS are more 'into' care in the last days of life than the care home staff.
- May give staff peace of mind to carry on with their duties knowing someone is watching over one of our residents and will ring for us should the need arise.
- It might be very supportive for staff that are not directly involved in care such as new domestic staff who have to go in to a resident's room to clean etc. and are apprehensive about what they may see.
- To bring a little bit of the culture of hospice in to the care home. To bring that focus of 'active life' in to the care home.

Matrons of care homes were open to learning new approaches. They thought that volunteers might act as a conduit of knowledge of practices in other care homes or from practice at LOROS. In addition there was some thought that their care home staff, observing the way volunteers were with residents, might allow them to adopt new ways of being with dying residents.

4. Apprehension about the Service

4.1 Volunteer perspectives

Volunteers were aware that LOROS ward nursing staff had rejected the addition of VALE to the ward service because they considered this as their role and valued the time they spent with dying patients. Volunteers understood why this was and supported the nurses in this view. Knowing this might perhaps have focused their thoughts on whether similar views would be encountered in care homes.

"*Will the nurses in the homes think that we are assisting them or a bunch of meddlers encroaching on their territory?"*

" Might they see us as a bunch of enthusiastic amateurs muscling in?......If they've got attached to someone, have been looking after them for years and right at the end they get someone else to come in and sit with them."

" Will they be used to volunteers or find our role difficult to integrate, at worst thinking we may be monitoring them in some way."

Other concerns voiced by volunteers fell in to four areas:

4.1.1 Their ability to provide a 'good' service

- Will we be a hindrance to them [nurses in the care home]?"
- That a person may have more than one of us & be confused by this.
- make sure we ask the right questions to get the right information about patient and family dynamics.
- The family might see us as an intruder
- Knowing what to say/how to approach it if the relatives were there and emotional?

4.1.2 Team working with care home staff

- The consistency in the way staff communicate and utilise the service
- some people may be threatened by the role and over protective of their own
- To feel part of a team and to be aware that care homes can be territorial break down barriers.
- Not enough information of working systems in that care home. To have a feeling of them and us taking over.
- That my role is not fully understood
- Care home staff may feel we are monitoring them in some way
- Avoid our inappropriate attempts at problem solving or making judgments. How information would be shared effectively between the care staff and the volunteers was seen as crucial to this.

4.1.3 Their availability to provide the service

- responding rapidly to resident need
- being called at night

4.1.4 The unknown

" you've got to be flexible because no two people die the same….some just fade away and someone else might fight it."

The was some apprehension as to whether the service in reality would be for residents who had no relatives or whether it would be also or perhaps more common to be needed for patients who did have family: either because their support gave the family a break, or to provide some measure of support for the family. The latter scenario was something, which was flagged as a concern by some volunteers.

"…. And the training seemed to be directed quite a lot towards dealing with families as thought the perception was that we were going to be sort of involved in family dynamics….. especially if there'd been some sort of agro… and we would be in some way trying to sort all this out and sort of pacify people. And I remember sitting there in some of the sessions thinking this isn't really what I'd sort of thought it would be …. I sort of thought it would be for someone who'd got no one to be with them right at the end."

Some voiced concerns about whether they would need to document their visits and where this would be. The processes of communication with the care home team were an area in need of clarity and development.

4.2 Care home perspectives

Matrons openly discussed their contemplation of potential concerns and risks in developing this new service and collaboration.

"*Originally my nursing background caused a few hackles to come up….We do that! My staff do that!….. but when I sat back and thought about it… they're not there to replace us, they're really replacing the family. That's how I've helped my staff get their heads around it."*

" I think some of the staff may need convincing…. That it's not someone who is going to take over from them…. or someone who is seen as perhaps spying on them. It's always strange when it's someone different who is in a professional role."

In addition to concerns about the realistic availability of the volunteer when needed concerns and perceived challenges for the new service as perceived by Matrons and other staff we completed a questionnaire fell in to six groups:

4.2.1 What residents and relatives may feel

- Relatives may raise a concern that some residents get care from staff and 'we only get volunteers'. This might challenge the care home that they were not providing good enough or equitable care.
- What would they think if a volunteer was there when a resident actually died and not them? Would this be any different than a member of the care home staff being there?

4.2.2 Risk to care home in provision of appropriate care

- CQC risk assessment might need to be undertaken
- Appropriate training would need to be in place e.g. hand hygiene
- Accountability for necessary documentation and paperwork

4.2.3 Team working

This raised the greatest proportion of comments. Some were practical operational issues and others more related to the environment and culture of the care home .

- Information sharing about residents with volunteers might need guidelines. How much information needs to be shared about the person and about their illness for the volunteer to feel OK in that room?
- The new service needed sufficient clarity from all parties. They were not to be seen as a member of the team but as complementary and supernumerary. Care would need to be taken not to use VALE as replacement for staff. The volunteers were replacement for family not staff. Seeing the service this way would reduce the possibility of defensiveness and allow roles and duties to be worked out.
- The use of paperwork and accountability for the written record of events would need to be worked out.
- The potential change in relationship/dynamics between staff and residents
- How would issues that arise be dealt with by LOROS and the care home most effectively?
- Learning and sharing sounds really great…. But it's about getting to that sort of relationship which allows this to happen.
- Communication/handover from the volunteer to the care home team
- Reporting in and out of the care home would be essential.

4.2.4 The role of VALE:

- 'listeners' not 'doers'
- Care from volunteers would be needed not to 'tread on staff toes' or take over.
- The volunteers might get over protective and take on a role to exclude staff in some way, taking on more than is intended: acting as go between/advocate.
- How to listen a lot and not seek a lot of information (from staff or the resident): to 'take it as it is'.
- They might get in the way and serve no real purpose other than just sitting there.

4.2.5 Being scrutinized by outsiders

- Feeling safe to maintain the culture of the home without being judged "they might think we are being disrespectful"
- May only see the obvious and not the whole picture and make judgments not understanding the broader context of why things appear as they are.
- May not trust that despite appearances, the best is being done
- Questioning our judgment especially when we won't be able to invest as much time in explaining/discussing this to the volunteers as we will with our employed staff.
- Volunteers may discuss the care or experience in the care home with outsiders.
- "They will watch us"

4.2.6 Needs and perceptions of volunteers

There was some concern that the actuality of the role may not be as the volunteer expected it to be and that this might lead to problems for the volunteer.

"There's a lot of laughing here and that could be seen as disrespectful but it's life. The volunteers will have this idea that they will be coming in to a place, looking after a person that's dying, they'll have music in the background and it's going to be

surreal. They're in this little box. But really we've also got to have life going on outside as well."

- How will volunteers cope with sitting with someone for longish periods of time. I don't think I could do it. Families find it hard even for an hours visit.
- If residents or family confided in them how would they cope with the role of go between/advocate. This could be stressful.
- Volunteers may feel/will be scrutinized by staff. How will they win them over?
- Will they be seen as good enough by staff?
- Might it be overwhelming?
- It can be difficult sometimes to watch someone in the later stages of life, will they be up for it?
- Things change rapidly and they may arrive and not be needed
- Can they cope with patients who can not respond or who are rude and vocal?
- Residents who mostly have dementia can be challenging.
- Volunteers need to be clear of their role and not taken for granted by staff.
- It's a challenging role. Residents and families may treat them differently to the care home staff and they might be put in the position of something like an advocate which could be difficult.

Preparation of staff in the care home by the Matron was seen as key to overcoming some of the anticipated challenges in integrating VALE into the team in a way that they were supported by the care home staff. The culture in each of the four care homes was very different. The four matrons had worked in different ways to prepare their teams for the new service and allay concerns.

One care home thought that they might provide support for the volunteers through identification of a mentor, especially if the involvement of the volunteer with any resident went on over several visits. This mentor would be the member of care home staff (registered nurse or care assistant) who knew the resident well.

5. The Training and Preparation of Volunteers

Care homes considered that volunteers would need training in:

- Understanding dying
- Communication skills,
- Confidentiality,
- Hand hygiene,
- Understanding dementia
- Cultural diversity awareness: nutrition, religious, cultural needs.

In addition to talking, reading and listening care homes felt that volunteers might be involved in the following practical aspects of care:

- Giving sips of drinks
- Mouth care
- Combing hair
- Painting nails

- Hand massage

Volunteers thoughts on their training needs were broad, ranging from:
the practical

- Some help in being able to read signs of death
- How to comfort the patient if they need comforting, what I need to do and how to do it.
- In order to be effective and confident I want as much information as possible on dementia conditions.

and operational

- Our role if members of the family are also present.
- To follow a policy and guidelines and therefore be able to work in this these strategies. To know boundaries, that will highlight areas of concern.

to philosophical.

- Most importantly, being reminded that people who are at the end of their life have been 'active' people with all normal hopes and fears and aspirations during their lives.
- To share with others their thoughts of the needs of people who are dying

5.1 Evaluation of the Training

Table 2. Evaluation of training programme by the volunteers.

	Strongly Disagree	**Disagree**	**Neither Disagree or Agree**	**Agree**	**Strongly Agree**	**Unanswered**
I feel the training has prepared me well for my new role			1	7	1	
I understand what being with someone as they die might be like		1	1	6		1
I have developed my communication skills on this course				9		
I feel well prepared to be alongside people of different faiths, cultures and languages			3	6		
The training has increased my enthusiasm for my new role			2	4	3	
The training has increased my confidence for my new role			1	7	1	

The training was welcomed and found valuable by most volunteers (table 2).
" It left me feeling that when the call did come, that I was as confident as I could be in the situation, with it being my first call out, to deal with it as best I could."

Those who had a nursing background commented that it was a useful recap but that they had learnt little additional and that the role was not one in which they particularly needed development.

" I think you've got to want to do it anyway. I mean if it's something that you're going to shrink away from then common sense would say that you wouldn't put yourself forward for it… I mean the training helps you to put it all a bit more in perspective and gives you an idea how to… things like health and safety."

Those that had no nursing background found it especially helpful and reassured them that the role was indeed something that they wanted to do and could cope with. The focus on development communication skills was especially noted as helpful preparation for the role.

"*The role-play they had, which kind of, you know, it really shows you, because the actor was fantastic, he just went in and out of roles and it was very emotional as well, it was absolutely really, you know, I mean, that really, I think that kind of helped to understand more, especially how a certain person, a calm person will take it and a person who thinks why is this happening to me, you know, it was, that was really worth it."*

Some volunteers questioned as to whether the training went beyond what was needed for the reality of the situations volunteers would actually be involved in.

" You would be with them right at the very end stage when you wouldn't really particularly need to consider the mental state either in terms of Alzheimer's."

Others found the dementia training very helpful and thought it relevant to their role. Impressions of the value of the training appeared to be influenced strongly by the role of the VALE service as perceived by the volunteer i.e. what they believed they were, and what they were not, 'signing up for'.

Not everyone however thought it good use of time and resources.

"This is something that I have done before anyway and I don't really consider that I required any formal training for this in the first place."

Some volunteers found that the training provoked memories about patients they had cared for.

The training allowed a growing bond between the volunteers which some saw as important for the future.

"Friendships can be made in respect to helping each other find ourselves, and to give support to one another…..We need to feel safe to express what we feel or how a situation left us and know that this will be discussed within these four walls and nowhere else".

Volunteers found the opportunity to spend some time on the LOROS ward with the nursing team useful. It helped reduce anxieties about being with dying patient, about being capable of the role they were stepping in to and about past experiences that were unresolved or pervasive.
" *I did not want to go to a nursing home with the past experience of my father dying there alone…. I very much appreciated having a further insight into being prepared for end of life care….. By listening and being showed around LOROS gave me some time to appreciate what help is needed with the individual needs of the dying patient."*

Some, who had no nursing background, commented on how perhaps more preparation needed to be given about what volunteers would see.

"I think you can only do these roles if you've got a very strong heart and you can take -, as I said, I've got the opportunity to go round the wards and have a look at patients and see how they're progressing each and every time I come, because I do take notes in my mind saying oh this person was this last time I came and this time she's really gone downhill and, you know, you can see in their faces how much weight they've lost and everything, but with the VALE course, I think they should have taken us in the wards to show us all these progressions, especially for a person like me who's never done it, who's never experienced anything like this."

Some of the course trainers commented that the volunteers had higher-level skills than other professionals they worked with and brought a depth of insight related to their life experiences.

5.2 Comfort bags

There was some mention of these by volunteers. They were seen as beautiful but some wondered if they would actually be useful. They considered music choice as very individual and that there might not be facilities to play CDs in the care home room. Religious items would also have such an individual applicability. Hand massage was thought likely to be useful.

6. Putting VALE into Practice

6.1 **Introducing the Service to Residents and Families**

A VALE leaflet was developed to enable the care homes to share information with residents and their families. In some of the care homes new residents and their families were given a VALE leaflet to read and invitation to speak to the Matron about it when they first arrived at the care home.

Care homes indicated that they would include information about the VALE service in their newsletter. None of these newsletters were shared with the project so it is not clear if this method was in fact utilized.

Some comments from residents or relatives reported by the Matrons.

- Why were volunteers needed?
- If my (loved one) can still hear when they are dying would a new voice be scary?
- We wont need it as we will be there.

Volunteers also reported comments from the Matron about conversations and issues relatives had raised.

"So you aren't looking after xxxx anymore. You've called in other people?"

This was reported as being addressed by talking about the ‘added bonus’, if wanted, maybe at a time when family couldn’t be there.

Only one relative returned a questionnaire to the evaluation team. The VALE service was seen as something that would provide support at difficult times when it was not possible for family to be around. They also thought that their loved one might benefit from being able to talk about things that were difficult to talk about with family. The relative said they had no concerns about the service, would make use of it at a time that they were not able themselves to be there. They felt that the idea was a good one and reassuring in that someone would be able to take over if they themselves had to leave.

6.2 Introducing the Volunteers

Small groups of volunteers were allocated to care homes. Volunteers were given choice in the location and also the number of care homes that they felt able to work with, the majority choosing to be linked to a single home. The group of volunteers went to the care home together for an introductory visit. Volunteers reported how were impressed they were by the care provided for residents. All volunteers commented on how welcoming each home was and how the Matron and staff they met were enthusiastic about the new service and the volunteers.

Leaflets about the service were visible to the volunteers in some care homes. There was acknowledgement of some vagueness about how contact with the volunteers would be made and the need for evolution of the processes as all parties gained experience.

On the whole the impression of the volunteers was that staff were welcoming of this role but some volunteers mentioned an impression that some staff were thinking that they would take an important part of their care from them; having cared for a resident for some time they would want to be with them at the end.

Matrons discussed a little of how they handled this with staff.

“The objections I thought I’d get from staff was all up here (head). In actuality when I introduced VALE she was just quickly a part of the team.”

“ I say you’ve got two hours grace to do other things….. and they’re quite pleased with that.”

“I have to take it very slowly with my staff. They need to get used to it. My staff are very selfish: it’s our home: Very proud of the home, very possessive. I have to tell them very positively, look we’ve been chosen. This gave them a little motivation”

Each care home was asked to develop a guide for the volunteers on key operational aspects for working with the team: Where to put coat, toilet facilities, how to make a cup of tea, fire procedures, hand hygiene equipment, working with staff, telling staff when you arrive/leave etc. Some homes developed robust internal processes for contacting and working with volunteers. This extent of this varied considerably between the homes.

Care homes thought using the of ‘*getting to know me*’ or ‘*all about me*’ boards and books about individual residents with volunteers would be the most useful way of helping volunteers gain some understanding of the person they were with. This was feasible for those in residential care who moved there expecting a considerable length of stay but was less available for shorter stay residents admitted for nursing care.

7. Making it work

7.1 The LOROS 'brand'

The was considerable positive comment about LOROS from the four care home Matrons and this was a clear contributing factor to their willingness to be involved in the pilot. Other homes that have had preliminary discussions about the service held similar views. Thus the VALE service being developed and provided by LOROS appeared to open doors for residents to have this companionship and support.

Volunteers felt that they were valued *because* they were from LOROS. Staff and families felt reassured and confident. Volunteers felt that having a volunteer from LOROS was seen as giving the home additional cudos. Additionally one volunteer felt that the Hindu community think that LOROS 'does a good job' which would help in gaining acceptability from such residents.

"So they may not see you as a [volunteer], you know, and I think because LOROS carries that, I don't know, LOROS symbolises care doesn't it. I know some people have different perceptions of LOROS but people that work at LOROS, they have that, it's a hospice, so the majority of people think well, they're good people that want to do good things, so it does carry that with it."

Care homes felt that the LOROS label added value as LOROS's general reputation seemed to reassure residents and families that end of life care/the volunteer would be excellent because LOROS was involved in it.

7.2. Volunteer perspectives

Some volunteers reported regular telephone contact with the Matron of care home, which were welcomed.
"It's still ok for me to contact her regularly on a Monday morning to bring me up to scratch as to what is what."

" X was very positive about this project and positive that her girls are OK with it. She did say that she needed to be reminded about the VALE workers as, when things happen quickly, she may not remember we are there to help ease a situation for her staff".

Visits however were perceived as less acceptable.

" I asked if she would prefer that I popped in occasionally just to show our face and mingle, but I got the impression that this was less acceptable."

Some volunteers wondered if regular phone contact added a burden to the home.

When volunteers phoned they were sometimes told about people that ‘had died too quickly’ or died whilst waiting for permission from families.

“ When xxx rang the care home she was told that there had been a need for us but no one had rung us. They are going to make sure our numbers are on the staff notice board”

This raised the issue in some volunteers minds that staff *might feel comfortable* with VALE sitting with residents to give staff an opportunity to get on with other jobs, but *less comfortable* with VALE in the very last stages of care, perhaps because staff would rather be there themselves.

7.2. Care home perspectives

7.2.1 Discussing with relatives and residents

Care homes described how they discussed the service with relatives and patients and sought their permission. This was most usually a combined approach of some or all of the following strategies:

- Providing a VALE leaflet at the time of enquiry or admission,
- Having leaflets in an open location
- Talking about VALE in the newsletter that goes to residents and families
- Talking to relatives at relatives meetings
- Discussing the VALE service at the time of conversations about advance care planning,
- Discussing the VALE option for a resident at GSF team meetings
- Discussing the option to contact a volunteer at time when dying became a reality.

Care homes reported trying to plan ahead with residents and their families. Since many relatives were quite dogmatic about what they did and didn’t want and who could and couldn’t visit (e.g. church) this was not difficult to introduce as a possibility ‘down the line’. Matrons also felt that discussing the service in advance of a crisis arising allowed residents and families more control and peace of mind. Many relatives were reported as taking the VALE leaflet to read about.

On admission to the care home, although most families felt that the service was in principle a good idea, they often said that they wouldn’t need the VALE as they would be there. However the Matron’s reflected that often there were gaps in reality that made the VALE service a valuable additional support but that families would not really foresee this, and could therefore not really know whether they would want VALE until their loved one was actually dying.

One care home Matron reported that most of those families who lived at a distance or families with medical or nursing professionals in them said ‘*yes*’ to VALE when asked about it on admission. Some had said ‘*no*’ as they perceived that this was sub-contracting on the part of the care home and perhaps using volunteers was thought of as providing a service of lesser quality.

When mentioning VALE when the resident was actually dying however, Matrons recalled no negative responses to the service and often conveyed positive responses from relatives.

“ *For instance this lady she is seeing at the moment who is on the LCP, the daughter’s not coping very well with it all, and I said to her daughter, ‘do you mind if I use a volunteer to come and sit with your mother, she’ll just read to her, a bit of poetry, music in the background or whatever?’ and she said ‘Oh, I’d love it’. But when it comes to the end she wants to be there herself.”*

Families were reported as valuing the support and comfort such a service offered to them if the dying process went on for some time and they themselves could not sustain visiting.

7.2.2. Getting to know the volunteers

Care homes were generally glad of telephone calls from volunteers just to keep in touch. It became part of their regular routine and was not seen as burdensome. It helped keep the VALE service in the care staff’s mind.

“ *She rings up every Monday, she asks us what we’ve got and then makes arrangements to fit time around us.”*

Care homes commented on how their confidence grew as they observed how the volunteers worked with residents and the team. Their apprehension about boundaries and roles was assuaged.

“ She has a lovely manner. Very consistent. Just having a chat with the resident and explaining what she’s doing there.”

“*Staff found her lovely….. got on very well.”*

“*When anything bleeped, like the mattress or the syringe driver, despite being a nurse by background, she didn’t try and investigate, she came and told someone. But she didn’t go to the nurse in charge she went to one of the carers which made them feel better because she went to them and not over them.”*

Residents may be known by care home staff for many months, sometimes years in residential homes, and the importance of staff liking the volunteers that they were entrusting with the care of their residents was very evident. The forging of this relationship with staff, despite infrequent contact, is a crucial skill for volunteers.

Matrons commented also that getting to know the volunteers allowed them to be selective sometimes in ‘matching’ them to the needs of a resident or their relative. For this reason they felt it was useful to have a team of volunteers with differing characters, and skills.

There was no perception from Matrons that Volunteers needed to be included in team meetings.

7.3 Working as a bigger team not as individuals

Some of the volunteers began working more explicitly together as a pair or threesome, one acting as the lead contact with the care home or taking it in turns to ring in a coordinated fashion through the week. Some took the lead in coordinating input from others for residents who needed VALE. One volunteer worked with two care homes.

8. Being with Residents

Over the sixth months evaluated in this pilot three volunteers have visited seven residents in three care homes (table 3). Four residents had a single visit, one had two visits, one had three visits and one had five visits. Care homes had not infrequently sought more visits for these seven residents which were not able to be undertaken. In addition five residents were thought by care homes to need or benefit from VALE but died before a volunteer was able to visit. Volunteers were not with any of the seven residents when they actually died.

Data on total number of deaths in this period suggest that where VALE was implemented in the care home from the start of the pilot, one out of four deaths had the involvement of a VALE volunteer.

Table 3. VALE activity August 2012-February 2013

Shaded rows indicate those residents that VALE had contact with; unshaded boxes are contacts with VALE by the care home but a volunteer was unavailable before the resident died.
V= volunteer
N= Nightingales
HL = Hunters Lodge
CC = Cedar Court

Date	Volunteer	Resident	Comment
21.9.12- 12.10.12	V1 & V2	1N had family who did not visit.	5 visits. RIP 14.10.12.
03.10.12	V2	2HL Son visited frequently including with volunteer	3 visits over 5 days. RIP 8.10.12 with son present
08.10.12	V2	3HL	RIP within hours of identifying need for volunteer and before volunteer arrived.
11.10.12	V2	4HL	RIP same day before volunteer able to go
23.10.12	V1 & V2	5N	1 visit by V1 V2 made arrangement to visit 26.10.12 but resident RIP 24.10.12
15.11.12	V1	6N	Volunteer not available RIP 17.11.12
08.01.13	V1	7N	2 hr visit RIP 16.01.13
22.01.13	V1	8N	2hr visit RIP a few hours later
28.01.13	V1	9N	Volunteers not available RIP 30.01.13
14.02.13	V1	10N	2 visits RIP 26.2.13
21.02.13	V3	11CC	1 visit VALE not available for further visits before resident died RIP 27.02.13
25.02.13	V3	12CC	Initial VALE visit then

			postponed by family. Resident died before VALE contacted again 26.2.13

8.1 The first contact

Some of the volunteers reflected on how they felt before their first visit to a resident.

" My mind is like cotton wool right now. I don't know what to expect my heart is pounding."

"I am exhilarated at going in but a little apprehensive- don't want to make a hash of it and that the Matron doesn't feel we are what she thought it would be."

" A little nervous today, chose a striped top- not too bright but colourful enough to catch the eyes of my lady."

8.2 Which residents and when?

Care homes approached VALE for residents that had no or very few visitors, where family were able to only visit for short times or when family needed to be supported to do other things.

"We've never used them in the last hours of life, they've not been there when the resident has died. We've used them as a relief for family in between times of their visits."

"*The Matron explained to the son, 'look we've got somebody, you know, just to relieve you', because he was sitting there all the time and 'your mum will be in good hands' and once he met me and he really thought, you know, this was a good idea as well, because I just sat there with him and we talked about things and other things as well."*

In addition sometimes other characteristics of the resident made the care home seek support from VALE, for example one lady called out a lot and was calmed by company.

The time of the visits were arranged when a volunteer was able to do this. Mostly this was in the day time. The data available is not detailed enough to be able to understand any patterns when care homes requested volunteer support which was not feasible . One of the three care home seemed to seek visits in the late evening/night and the other two in the day time. This may have been related to assumptions about the VALE service, care home staffing factors or resident factors. One volunteer commented on planning her visiting strategy to overlap with tea and shift change to support the staff at a very busy time for the care home.

The volunteers who visited the seven residents reported that each of them had been informed about the VALE volunteer visiting and where feasible their agreement had been sought. The agreement of family, if available had always been sought. The volunteers noted the following about their interactions with residents when first meeting them:

- Matron did talk to her but impossible to know level of comprehension.
- She appeared glad of the company.
- On one visit she said "thank you"
- She did know and was pleased

8.3 What did the volunteer do?

Some of the stories of visits with residents, as told by the volunteers in their own words, are included in appendix 1. The following were mentioned by volunteers as things they had done whilst being with residents.

- Read passages from a book found on the window ledge and commented on how sections related to life.
- Held hand & talked
- Visual relaxation intervention: the ship
- Prayers
- Read from bible
- Assured her she was safe
- Talked about things and places in common
- Talked about the journey and not being alone
- She was anxious – talked to her, held her hands and we did some visual relaxation therapy and read a few prayers. Before I left – assured her she was not alone, safe and I would come again.
- I read and then sat holding her hands – gently stroking them. She was relaxed but barely rousable.
- Gentle hand massage
- Sips of drink
- Very poorly- sat and read passage from my Bible and gently assured her she was safe.
- Unrousable – talked to her and read from my reflection. Told her family were waiting for her and were giving her permission to let go, her work was complete and not to be afraid – she wasn't alone. Before I left I read the Lord's Prayer and the Magnificat.
- Saying "I'm just here.- I just want you to know that you're not alone and don't be frightened, because I am here and I will be with you as long as I can."
-

Sometimes volunteers played an active role in responding to the questions of family.

"*And then, what was it, the second day once he got to know me the first day, the second day he took me out in the corridor and said 'you know, I'm really worried about my daughters, I don't know what to do, some people say I should tell them and some people say I shouldn't', I said, well I just kind of said 'look, whatever feels right for you, you should', I said 'but if it was me in your position, I would tell my children', because the girls were about 10 and 12 so, you know, I mean, it was better, I think in my opinion it's better for the children to know, at least they can go and visit their grandma for the last time and then instead of her just disappearing and they don't know what's happened to her, you know."*

"I assured her that she could be here all day and go out for a couple of minutes and her grandma could go- her choice and maybe spare the granddaughter from seeing her go."

There were apparently no discussions between volunteers and care home staff about LOROS or care of the dying *per se*.

8.4 Reflections of volunteers on the experiences of being with residents

Volunteers commented about both positive and more challenging experiences.

" *She was a lovely lady and it was really nice for me to have very first opportunity to have a nice person like that as well. You know, she was very friendly and then the second time I went she says 'what's she doing here, hasn't she got anything better to do!"*

"*The lady there, she was basically really -, she would open her eyes and she's really - she was just there - and the smell in her room because she was breathing whatever medications she had, that was really overpowering and for at least about 2 minutes I felt I couldn't breathe. Now that's personally me because of the smell, but then this lady didn't really engage in anything at all even if you -, her hands were all tucked in and so I didn't want to take them out. She was really, she's lost a lot of weight and is more like just skin and bones and that's really affected me at the beginning, but then it was OK and I sat for a couple of hours with her."*

Volunteers also reflected on the value and meaning of the experience to themselves

"I was honoured to be there, to be part of her life at the last minute and towards the end. I thought it was nice for her to see a different face besides her family and the nurses, whereas she could just talk to me and basically I just thought it was nice for me as well to have taken part in her life towards her end."

They also reflected on how they were received and supported by care homes staff and how a trusting and collaborative relationship was formed or the gaps in this from their perspective.

"Matron would tell me a little bit about them and then take me through to where that person was."

"Every time they were passing the room, they would come and say 'oh would you like a cup of tea, would you like to take a little walk' and they were really, really nice.

"I just felt like I was just there to play my role and that's it. I was there for about 2 or 3 hours and they came only once to ask if I was alright."

"I think the first time that I went and this lady was - she was sort of, was semi-conscious and I started just talking to her. I knew she couldn't reply, but I was talking to her and there were the nurses, going backwards and - I think they were as interested [laughing] as to what you were going to do. And they kept going backwards and forwards and I think I thought "they must think I'm absolutely stupid here" I'm sat talking and answering myself sort of thing and gradually, one of them did come in; she said "Are you alright?" and I said "Yeah, I'm, fine" and she said "Well, you won't get any replies" and I said "No, I know I won't" I said, "but her eyes are knowing that I'm there" - so that's - "and I'm quite happy just to sit here quietly and just occasionally, just say that I am here" - and, after that they were fine. And whenever I've gone they know who it is and they'll say 'it's X on the phone from LOROS – is there anybody?'"

9. Difficulties of making it work

9.1 The withdrawal of one care home

Langdale view withdrew from the project in November due to internal pressures of work. The Matron remained very supportive of the service in principle but was unable to dedicate time to make it work because of a change in her role and therefore also her deputy and other staff: it was "*just not the right time for us to do it well*". The care home had also taken fewer residents for end of life care as more beds were being used as a 'step-down' facility for rehabilitation and assessment.

The Matron commented that the owners of the Langdale Group of care homes had conveyed to her some concern about the workload that VALE might involve; specifically the time needed for integration of a new system and the necessary reflection and supervision. There was not a perception that the volunteers themselves would cause any increase in workload.

9.2 Are you available today?

When needed. volunteers were generally needed almost immediately. This was understandably difficult logistically. How this impacted on the care homes and the volunteers is important to consider.

9.2.1 Volunteer perspectives

Volunteers 'apologised' for not being available on the phone immediately or for not being able to visit. Some expressed guilt that they were not able to meet the request for someone to be with the resident and support the care home team.

" called to say I was going to visit at 2.30. By the time I got to the home she has passed away peacefully with her son by her side. I was 15 minutes too late. I was a bit upset, but was glad that her son was by her side."

" A rang me to say that the care home had rung to ask her to visit but she had visitors staying. She felt guilty that she couldn't go and so did I, as I had people for a meal. I did feel as if I was letting them down."

"So, I – I did feel ever so guilty about that, but it's one of them things – as you say, you don't know when they're going to go or anything else".

9.2.2 Care home perspectives

Nightingales care home, which had a high number of deaths, wondered if a regular timetable of visits from volunteers might be helpful for all parties in planning (volunteer, resident, family, care home). They felt they were likely to have a resident every day who would benefit from companionship as they were very poorly but perhaps not yet thought to be within days of dying. Homes with fewer deaths thought this unlikely to be a useful way of working.

9.3 Most residents have relatives

Most residents that died in the period of the pilot had family who visited. For most this meant that a volunteer was not needed to support them.

However the most frequent model that emerged for the VALE service was that they would support residents when family visitors were unavailable. In some instances VALE provided support for the family member directly

9.4 How soon is too soon?

It is almost impossible to predict when a person's is entering the last hours of their life are. However the VALE service was not developed a sitting service for residents who were stable but 'lonely'. The timing of the point of engagement of the service was often difficult. Volunteers and the care home matrons reflected on this.

" I know that 'sitting' with a resident in the loosest sense is not what we are there for, but I feel even if we are not at the very last breaths, in most cases, our project is being talked about. This goes against the grain with most of the team, but I am happy to go and sit a few times to help the family and they know if it were sudden, and they are unable to get, we were there when the time came" (volunteer)

" We cannot pinpoint a day, an hour, or a minute, when the end comes but before that, the lady can feel relaxed and calm, as she goes on this journey and knows that she is not on her own while one of us is by her side and the daughter feels happy about this and I feel comfortable taking this road." (volunteer)

" Maybe we will have to put a little time in with that person before they die. This is not to be considered as a sitting service we are performing but forming an alliance with that person where by they feel comfortable and accepting why you are there and at some point are ready to let go and be safe to go with us by their side." (volunteer)

" It's not quite a sitting service because they are with people that are dying…. But some people die quite slowly" (Matron)

"When it comes to that time it is better to have some relationship, so their face is known to the relative/resident. " (Matron).

"A little bit, not too much. You don't want to be involved in their lives that much, like the first lady, I thought that was just right, because I got to know her a little bit, I wasn't sitting with a stranger, at least she knew me, she knew my face, she knew my hands, whereas the other lady, she didn't know me, I had no conversation with her, I tried, but there was none" (volunteer)

Some volunteers offered that view that some relationship with residents needed to be built to give the best to people in the dying phase

" Without volunteers making some kind of approach to the home and to poorly residents I feel that what were are trying to do will be a little bit of a hollow gesture and that staff will feel that their resident has been cheated at the end because a 'stranger will be with them'."

Views were also voiced that it was important to avoid the potential that dying residents may perceive a stranger close to them and feel distressed by that.

However, volunteers also perceived that getting to know someone a little earlier may not be possible because there might not be time, the resident might not want it or the family might not want it at an earlier time in the resident's illness.

"I think, if somebody has got relatives and the relatives visit frequently, they might – even the relatives might resent it, you going. But if the relatives live away, they may be grateful that somebody would go and see Mum."

9.4.1 Should longer relationships be forged with residents?

Some volunteers considered in depth whether they would want to know residents, and form a relationship, before the last days. Often they concluded that this would make the job too emotionally difficult for them.

" I haven't had a call yet so I called to see what was happening and was invited to visit. I sat with a lady and we talked. At that time I thought I would visit them regularly. When I was driving back I thought no I wouldn't visit again because I might get attached to these people and I might not be able to do my job properly."

Some volunteers who tried visits to care homes to keep a profile found them quite unsatisfying. Care home staff were very busy and the lack of real role felt as if time was not well used.

Some definitively did not want this role, others could not commit to the time that would be required. Others would not want to because it might increase the impact on them of a resident dying. Concern was voiced that they may become an unpaid pair of hands, supplementing and filling gaps in rather than complimenting the care home services.

"There was talk of, in the very beginning of being like a friend of the home, so you could go and visit the home, perhaps not every week but perhaps a couple of times a month or once a month just to, again, remind the staff who you were, that you existed so they got to know you and go round and get to know some of the residents. And I think as I say some have probably done that only it wasn't something that I felt I really wanted to get into doing that. I don't really know why. I think partly because I didn't feel I'd got time."

Volunteers were clear about the focus of their role on the individual patient/resident. They were concerned that regular visiting to homes would dilute this. They did not see their role as a "friend to the care home." They also wanted their time to be spent usefully and not going to the care home with no clear purpose for their visit.

9.5 The numbers of residents who need it in any one care home are small.

Some volunteers had seen from the time they first met with the care home team that the numbers of patients dying who might need a VALE was likely to be small. They held this in their minds through the pilot and wondered if linking with serving ore care homes or working within the hospital would be future strategies.

The nature of care homes also appeared to change during the pilot, some taking fewer residents for end of life care on discharge from hospital. This was a strategic, business based, decision.

10. Supervision and Support

Volunteers considered their needs for support in their role before they started the VALE service.

10.1 What Support do you think you will need as a VALE Volunteer?

From LOROS:-

- Feedback, initially sharing experiences with the other volunteers
- Tailored training
- Flexibility on times that can be covered
- Someone to be there if I have any questions
- Reflective practice team meetings
- Someone to share any thoughts or worries with
- To be able to have someone in the background to 'sound out' any fears or emotions that may come up.
- Being able to access someone for help when necessary
- Access to someone if I need to discuss any practical or emotional problems
- Opportunity to discuss any difficult issues that may arise during any visits

From the Care Home:-

- Not being left unattended for long periods.
- Acceptance as a member of the 'team'
- Openness, respect and transparency
- Feedback, knowing their expectations

In addition to 'as needed' access to Shani Faulkner the service and project manager, volunteers were given the opportunity to meet with Shani Faulkner and Helen Newman on a regular basis both to review any operational issues and to access support of LOROS staff and of other volunteers. For some this level of structured support was unnecessary.

"I don't need to constantly evaluate my feelings and emotions and neither do I have any doubts or fears about my ability to carry out this work….. I can't help but feel that this pilot is being overcomplicated. I appreciate the need for 'support' when it is necessary."

Others found it more useful than they had anticipated. However, the feeling of the group meetings was perhaps understandably dominated by the lack of contact with dying residents and how disappointing this was for the volunteers.

Some volunteers (who had been involved with residents) reflected on some of the characteristics or traits that they had learnt that a VALE volunteer needed. These were:

- Flexibility of being able to adapt to an individual resident's needs and behaviours and differing care home cultures
- Resilience in being able to walk away from sad situations
- Communication skills with staff, residents and relatives

One care home Matron reflected on what volunteers may encounter and their need for support. The attachment to residents and their families, which may be forged rapidly in these intense, emotional and intimate situations, should be anticipated and the consequent feelings of loss when the resident dies, be supported.

11. Adding value

Volunteers and care home staff were given a structure questionnaire seeking their thoughts after a resident who had had contact with a VALE volunteer had died. The Matron of the care home was also asked to seek this feedback from relatives if they felt it appropriate to do this. Two volunteers completed these on 3 residents who had died. No staff or relatives gave any formal feedback. More plentiful evidence was available from the interviews with each care home Matron and each volunteer and from some of the reflective diaries kept by the volunteers.

11.1 Feedback from relatives

There are no direct reports or comments from families. There are several comments reported by care home matrons directly or volunteers or after conversation with care home Matron

“ Her daughter expressed her thanks for the input, we, VALE, had put in for her mother….. happy and very grateful”

“He was pleased it all went well”

11.2 Feedback from care home staff

There were numerous comments from care home Matrons identifying the value of the care provided by VALE for residents, for family members and for the care home team. It made a big difference to care homes at a time when the needs of residents were hugely increased.

“VALE just sat and read and I do believe that settled her, even though she had lost her ability to speak in English. The staff wanted the book left so that they could carry on reading…… the reading seemed to have a lasting effect, she was much calmer. We had asked the GP to review her agitation and actually when he came and saw her she was clam….. we had to tell him we were not lying!”

“ I think it helped the resident get what she needed without upsetting her son.”

“ Although we only used the service once it really gave him peace of mind. He didn’t want to go but he needed to go. Because he found it really difficult to be with his mum all the time. But the guilt …. She was brilliant. She gauged him really well and spent time with him too, talking about all sorts. Although he’d spoken to us about his mum dying, I think having the reassurance from someone else about what is happening with his mum is a natural process. I think it helped her son a lot. I think the reassurance that it was Ok from someone external to the home helped him.”

“It was invaluable at the time. It really gave us peace of mind that someone was in the room with M…. And that they would alert us if her condition changed.”

“ If she wasn’t there then staff would have had to do extra time or it couldn’t have been done. We really appreciated that.”

“Care staff feel guilty when they have to leave someone on their own and knowing someone is with our residents gives us peace of mind.”

“You just took a deep breath and knew you could get on with other things.”

“ It was really calming, for the resident, the family and for us.“

“ It’s nice knowing that there is someone in with them who can tell us when something isn’t quite right. Sometimes they notice things because they’ve had time to sit with them. And families are so reassured, they’re because their biggest fear is them being on their own. You can jus take a breath and know they’re alright, they’ve got someone in with them.”

“ She was lovely . The way she approached staff if she was concerned about something …. You didn’t feel like she was nagging at you… you just felt like you were on the same team. It was lovely. She just fitted in with us and the family.”

That all this can be achieved by volunteers in such short spaces of time is truly remarkable and a real tribute to them and their preparation for their role.

11.3 Feedback from volunteers

Volunteers reflected on what they perceived they had achieved, drawing directly on their experiences and on their more global impressions of their role.

“Two hours out of so many we flutter away- but these meant all the world to her and to me.”

“She formed the words ‘thank you’ and it made me feel so humble’.

“I don’t think she was aware that I was there”

“I do believe that this lady was pleased that we were able to give her that time just to be with someone and by the look on her face this was very much appreciated and important to her.”

“I feel that we are taking the end stage of life in to a ‘comfortable’ stage- the dying person feels comfortable to have someone there who they have begun to recognize and feels less fearful and anxious and the tiredness and can begin to turn to relief and acceptance and willingness to begin that journey.”

One volunteer drew on other experiences as a volunteer in expressing what they thought the added value brought by VALE might be.

“I’ve found that as a LOROS ward volunteer that people are keen to tell a volunteer things that they’re never going to tell other staff because everybody is so busy and they will give their standard answer ‘don’t worry about me’ or ’I’m fine’ but when the

staff are away they say "I'm frightened. I don't know what is going to happen to me" or "look at the state of me'. We've got more time and they're less embarrassed.

12. It didn't quite take off: Ahead of it's time, a slow burner or an unworkable idea?

12.1 Volunteer perspective

Volunteers reflected on the low uptake of the VALE service and the impact this had on them.

"I don't hold anybody responsible for this it's just the way it's worked out. You know I'm not angry about it, it's just slightly frustrating."

"On the face of it the homes seemed like a good idea at the time because the old sort of long term hospital care settings like I alluded to from the Towers, they don't really exist now and it is the smaller homes. So everyone's gone out to these, private homes are looking after all these people with Alzheimer's and everything and terminal conditions. "

"I've pretty well gone off the boil with it all, with nothing happening."

Those volunteers that had supported residents were more motivated to continue working as a VALE volunteer than those that had not had this opportunity. Some because they had already moved on to other ways to achieve what they had wanted to do in this role and some because of reflecting on the experiences of their colleagues and of the VALE service.

Some volunteers felt that care homes '*forgot we are here'* and that systems within the home, especially a dependency on the manager to contact VALE, might have placed a barrier to the service being used more frequently.

"I think what happens is, if Matron isn't there, I think they feel they've got to – that normal nurses have got to speak to somebody else to get permission to ring."

Volunteers also wondered, but had no evidence of specific reasons for the concern, if the publicity given to the service and the depth of awareness of the care home leadership and staff had been sufficient to optimize the access to the service.

"You've got to get some rapport, I think, with somebody, to feel relaxed and comfortable – 'I'm coming to my end and I'm okay with that person.' And I don't think you're going to do it any other way, than going in and having a couple of hours or even just half an hour, and saying, 'Well, you know, I'll come back another day – am I okay to come back another day?' – while they are either coherent or semi-coherent – and, if they have got family, for the family to say 'Yeah, I'm quite happy that that person's coming in. I know I can go to work and I know somebody's going to be there'."

Some volunteers that a processes needed to be developed to overcome the problem of the immediacy of need and the availability of the volunteer. If care homes contacted one person/volunteer that person should then ring others if they themselves weren’t available . Thus volunteers took responsibility for co-ordinating the service as well as providing it. This is begun to emerge in a small way (usually pairs of volunteers) working with one care home.

12.2 Care homes perspective

All three care homes wanted the service to continue and grow.

“*Yes. Without any hesitation. I think it is a really good service. I think it something that homes desperately need. We have got residents that don’t have living relatives or who have elderly relatives who are not going to be able to be with them and stay with them. I think it is ideal. It’s nice to know that there is someone where. When you do need to use it, it really matters.”*

Matrons thought that homes in generally really needed this service and the educational links with LOROS. None of the care homes thought that they would ever develop a similar service for themselves and really valued the training and support for volunteers that the partnership offered. In addition appropriate recruitment of volunteers was seen as more feasible through LOROS. One example of where VALE had been used identified that this might have made a slight cost saving to the care home, as they would have had to cover the gap with additional staff (as indeed they did at night) if the volunteer had not been there.

Some perceived that a future challenge for the service (and for end of life care globally) was the potential that care homes in general become less willing to accept residents who are near the end of life because of the funding was changing and the fact that more funding is being put into care of patients with dementia.

Whilst one of the three homes would feel comfortable calling for ‘a VALE volunteer’ two of the homes felt at least some reluctance to call on a volunteer from a wider group who did not have specific links to the care home and who the staff had perhaps never met. In addition might reduce the opportunity to ‘match’ the resident to the volunteer.

12.3 Wider impact of the VALE pilot

A few additional pieces of information have suggested a wider impact of the VALE pilot.

- Care homes Matrons mentioned that the Care Quality Commission compliance officer had picked up on VALE as a very positive development. He had brought the idea up with other care homes and many had expressed an interest.
- LOROS has recently received an enquiry from a care home, which was not part of the pilot, seeking a volunteer to sit with a resident that was dying and needed support.

Care home Matrons mentioned that their use of education services at LOROS had increased because of the link with the VALE pilot. This included both sending staff to study days and the support of the practice development team within the care home. They felt that this would not have happened if that had not got to know LOROS so well through the project.

13. Conclusions

The VALE service has made a real and important difference to residents, families and care home staff and was valued by care homes as an important addition to the care they could provide at the end of life.

That this can be achieved by volunteers in such short visits to residents in care homes is truly remarkable and a real tribute to them and their preparation for their role.

Relationships with two care homes were well established from the start of the pilot. Relationships with the third care home was slower to establish and one care home found that they did not have the capacity to support the implementation within the home.

Three of the nine volunteers had opportunity to support residents. The way they did this was different for each resident. Sometimes they seemingly provided just a presence in the room. Sometimes they had physical contact, holding hands or massaging. Sometimes they provided words either reading, or with guided imagery. Religious readings and prayers were a feature for some patients.

Initially volunteers worked as individuals but this evolved to some working as small teams who co-ordinated their input. This was probably a more successful model and working as a larger team might have been more successful still as there were calls that care homes made on the VALE service that were unable to be filled by the service.

The pilot has found that the need for VALE is infrequent, probably around one in four deaths. The most frequent model that emerged for the VALE service was that they would support residents when family were unavailable. In some instances VALE provided support for the family member directly.

The challenge of such a service is how to be flexible enough to be available almost immediately and for an intensive period. For any individual care home there is an infrequent need which raises challenges of keeping the service and the contact processes on the radar of care home staff.

That LOROS has developed this service for care homes is seen as appropriate and welcomed by care homes. The LOROS branding was seen as a quality assurance label by staff and families. It also perhaps enabled families to focus on seeing that the life of their loved one was drawing to end. The LOROS label seemed perhaps to enable them to be more open about talking about their concerns, regrets, guilt and wishes and there are glimpses that VALE helped them achieve things with their loved one which might otherwise not have been the case.

14. Recommendations

The VALE service is very valuable and ideally should be available to residents in care homes. To do this LOROS needs to work with care homes to develop a service model that is acceptable to all parties, workable and affordable. The most successful model is likely to be one of a pool of volunteers serving a pool of care homes with a clear system for a single point of access by care homes to VALE and subsequent co-ordination of volunteers by a volunteer co-ordinator. Care homes with deaths mosts weeks would benefit from regular planned volunteer input for support of residents who are very unwell.

LOROS will need to drive the future development of the service but there is a willingness of two of the three care homes to work with LOROS on taking this forward. The support of external bodies in future development such as the CQC and social service quality or education units should be explored. The availability of grants for further development and commissioning of ongoing service should be explored.

Individual care homes are likely to want to know the volunteers individually to build confidence in entrusting the care of their residents to them. Similarly individual volunteers will want some familiarity with the care homes that they attend. This will be difficult to achieve and as confidence in the service grows this may evolve. It may be that the LOROS branding provides sufficient quality assurance for some care homes and that individual volunteers are welcomed as part of a valued service. The care homes are likely to vary in this.

Appendix 1.

Some stories

Story 1

"Matron introduced me to her and then I spoke to her on my own. Told her who I was and that I was from LOROS and here to sit with her for a while. The radio was on and music from classic station was playing softly in the background. This lady had a syringe driver and sister came in to change it. She exchanged pleasantries with this lady and myself- there was no response from the lady but her eyes were flicking open and shut. I repositioned the arm chair that was in the room and slightly lowered the bed telling the lady what I was doing so that we could have eye contact as her head was positioned that she could only look upwards. I gently repositioned her pillow and told her why and what I was doing so it gace her more support to her neck, shoulder and face- she shut her eyes and then opened them and tried to move her mouth. I let her settle and spoke about the music and what I imagine we were doing while this was on- sailing on a ship in the sunshine and deep blue water, the sound of the hull as it parted the water and the waves gently folded back. This she appeared to get into and I asked her where she was going as the open view had yet no ending- only where the sea would meet the sky in the distance. My lady seemed relaxed and I touched her hair line and gently stroked her hair – "like all mums do" for a tired children.

We stopped like this for over an hour – sometimes she moved her legs a little or purser her lips and I assured her I was still there, so she could relax and sleep a while- which she did and I left her after 2 hours. She was in a deep sleep but I spoke softly that I was going and would call again."

The resident died 9 days later.

Story 2

The elderly lady had been able to speak English but as she became more unwell she reverted to her native tongue only. She had a son who lived far away and had previously had friends visit her but these have tailed off. The lady called out at times, as if in pain but the care home Matron felt that she wanted company most of the time and that a volunteer could support the care home team in providing this for her. There are three perspectives on parts of the story of VALE with this lady.

" I read to her and she was settled and at no time shouted out. While I was sat reading I am sure she was listening and I felt that she was pleased to have me there for her, to have attention slowly for her, and she was listening above all the noise that was outside her room. I feel she enjoyed having the company and I have been able to fill that little space of her life with a very simple act, it is very humbling."

"I went into her room and there is an overpowering odour in the room. The odour is coming out of her mouth, because she breaths with her mouth open and her eyes are closed.
I was introduced to her, but hardly any response.
Her room seems comfortable overlooking the gardens.
Couldn't hold her hands because she was all tucked in. She is very thin. I am getting no response from her.

I read a little verse from the Bible and also a couple of Psalms. I talked about myself but still no response. I sat with her for about 2 ½ hours."

"And then, the other lady we used the volunteer for we – I suppose, really, have a bit more used and abused in a way because this lady was on and off the LCP like a yo-yo and everything was inevitable, it was just the timeframe. So, she used to visit her every week – I just felt – 'cause she had no family, at all,– so, she used to visit her every week and come and spend a couple of hours with her on a Friday morning.
And I think the last week of life, or whatever, she came, I think, two times, but it's always been between Monday and Friday. She was there and she read to her and – just not far from my office, actually, so I overheard everything and I kept my eye on, to see how things were going. And I would say that, her manner – I found out, afterwards, she was a nurse and what have you- but her manner was lovely and it was consistent. It was 'having a chat' to the resident , even though there was nothing coming back and explaining everything she was going to do, even if it was she going to now go and have a cup of tea, you know, – so it was very nice that was. "

Story 3

"At the home the Manager told me that she is under palliative care and she didn't have a good night. I was introduced to her son.
The manager told me the lady was suffering from a severe arthritis. She doesn't want to talk about death or dying. She has been at the home for 3 ½ years, only reason she is here is that her son couldn't look after her because the arthritis was getting worse. He was so upset about that. I was told that both mother and son were very distressed and tired because it took the hospital more than 24 hours to discharge her. The hospital kept on delaying and delaying.
Once in her room, it looked comfortable. She was asleep in the chair. When I walked into her room I was told that she is on oxygen all the time. She looked very pale and thin. I was introduced to her, I think she liked me, she gave me a smile.
Her room had photographs on two walls of her when she was young with her husband and friends and one wall had her granddaughters photograph.
After a while I assured the son that I would be alright with his mum if he wanted to go out, so he went out.
We talked a little at a time. I lived in Melton Mowbray many years ago, so we had something in common because she was from around Melton. We talked about the Tuesday cattle market and her 2 granddaughters. She is very proud of her little family.
Son walks in with some ice cream. She ate it all. Then she started feeling sick. I called the nurse by using the call button. They explained how to use it when I first came into the room. The nurse gave her some tablets but she couldn't swallow, so she crushed it and gave it to her with a little ice cream. They were going to give all her medicine in liquid form.
Found out that the son was getting very upset. So we talked outside the room. I think I was just listening to him. He just needed to talk to someone. He just talked about his daughters. I didn't want to ask him how he was feeling about his mum.
When I was ready to leave about 2:30 the son asked if I would visit again the next day and I agreed that I would visit.
The staff are very good, while I was with the lady on my own they would come and check if I was ok.
I left about 2:30 promising that I would return the next day.

Walking into the room she looked like she has lost a lot of weight overnight. She was coughing a lot. She has bruising on her legs, left hand was twitching and was feeling sick. Staff are very good, they can't do enough.
She is breathing with her mouth open. She said didn't I have anything better to do. She still had a strong voice. Very nice lady she never complained once. She still appreciates when anyone does things for her. She doesn't like taking medicine.
Son not doing well today. While she was asleep, I stroked her hand and she seemed to like that.
Son stayed until 2 last night. He seems to like me coming. He doesn't know whether to tell his daughters how serious his mum is.
She is very tired today. I sat for about 3 hours.

By the time I got to the home she had passed away peacefully with her son by her side. I was 15 mins too late. I was a bit upset, but was glad that her son was by her side.
I really wanted to see her one last time before she passed but that wasn't to be. At least she wasn't suffering.
Talking to her son he said he broke down when she went, but now he was better. He gave me a hug.

I was asked if I wanted to see my lady. I wanted to see her so I was taken to her room. She was all dressed up with her teeth in and her glasses on. She looked so peaceful. I held her hand and said "goodbye".
This home showed so much dignity. I was very glad that I had been given this opportunity to sit with this lady. She was a lovely lady. Everyone liked her at the home. May she rest in peace. "

Story 4

"Thursday 7.15pm. I received a call whilst I was at art class. I had to give someone a lift home so I went straight after that. When I arrived someone met me and told me about the lady who was ill. Up until Tuesday she had been well and was one of the more lively residents.
I went into the room and introduced myself and I said I was going to sit with her for a while. I don't think she knew I was there though.
The girls brought me a drink and I sat with the lady until midnight. Her breathing kept changing- sometimes it was very noisy.
When it was time to leave I said my goodbyes. The girls had come in several times to make her comfortable."

The resident died 3 days later.

Story 6

" The lady is in the latter stages of terminal care, comfortable and mouth care being carried out. She has a large abdominal mass and also dementia- no problem with this as the lady is bed bound and unrousable. She is very pale but has not yet taken on that waxen look but looks comfortable. The daughter and granddaughter both work and are unable to attend in the daytime, but Matron has spoken to the granddaughter when she rang to say grandma is deteriorating rapidly, maybe to call I this afternoon.

I sat by the side of my lady and spoke quietly that I had come to sit with her for a while and said who I was and where I had come from (LOROS). There was no visible flicker of movement either with her eyes or mouth. Her breathing shallow. I talked about the snow outside and the birds on the bird tables and said I would like to read to her for a while so that she would know someone was with her and not be afraid of being on her own. We read from the reflections and spoke about the sailing ship and when the time came to say goodbye in this journey , her friends and relatives and husband would be welcoming her at the next stage of her journey, so in fact she would not be alone.

I do not know what her religion was or whether she had a faith, but together, I am sure, in her mind, as I spoke the Lord's prayer, she was saying it in her mind. Just before 2.30pm her granddaughter came in to the room and she was pleased that her grandma had someone with her. The granddaughter talked about how bubbly her grandma had been but how quickly she had deteriorated. The granddaughter became upset, she had sat with her granddad 5 years ago, and that it was not a 'happy' death and it was not possible to come and sit all day. I assured her that she could be here all day and go out for a couple of minutes and her grandma could go- her choice and maybe spare the granddaughter from seeing her go. She wished her grandma would go without her knowing-just slip away and the granddaughter not notice.

I watched my lady take on a different appearance- her breathing was very shallow but not labored and she had taken on a very serene face: she looked very much at peace with herself. I talked to the granddaughter how her grandma looked so peaceful and content, maybe, as the hearing is the last thing to go, her grandma had been assured that her granddaughter was beside her and that her time was nearing to le go and I felt maybe her grandma was waiting for them to give her permission to let go- her work was done and family on the other side were waiting.

I thought it was time for me to leave and let the granddaughter have time on her own to sit and talk to grandma for a while. The granddaughter said that she was so pleased to know that I had been an that she was glad of the chat we had. I said I would ring on Thursday to enquire if we were able to visit but that I did not think it would be long. I think this helped her put into perspective how near her grandma was as earlier she had been upset that grandma was not eating or drinking and I tried to explain why this was no longer possible. As I stood to go she moved towards me with tears in her eyes and I gave her a big hug- she thanked me for that and I said goodbye to my lady and wished her a safe journey."

The resident died a few hours later.

Appendix 2

The methodologies

Volunteers

Volunteers all completed questionnaires at the start of the VALE pilot, after the training programme. They were asked to complete a reflective questionnaire after the death of a resident they had sat with**.** Three were returned (one incomplete). At the end of the project the volunteers participated in a one to one interview.

Volunteers were also asked to utilize a ***Reflective diary.*** Some used this extensively, others very little. One found it annoying and it became potentially detrimental to the project. The volunteer considered withdrawing because the diary methodology (and supervision sessions) appeared to imply the need within the service for volunteers to 'constantly evaluate my feelings and emotions.'

" I also find it quite irritating being asked to maintain this reflective diary. I realize that I might be regarded as being emotionally sterile in some way, but I don't feel that I am….. It is very different when it is someone you know and love, and I sometimes feel that this distinction isn't being made"

Another kept it because they were asked to *" I'm keeping the diary because it is expected. This is not a way of clearing my head that I would choose- I would much rather talk to trusted person(s)"*

One used it to record feelings related to personal encounters with friends and family dying.

Care Homes

Care home Matron all completed a questionnaire at the start of the VALE pilot. Seven additional care home staff completed a questionnaire at the start of the project. The four Matrons also participated in a one to one interview at the start and at the end of the pilot (or on withdrawal from the project). The care homes were asked to complete a questionnaire after the death of a resident that had had VALE but none were completed.

Residents/families

A questionnaire seeking views about VALE was developed and care home Matrons were asked to share this with residents and families where they felt it appropriate. One was returned.

Appendix 3.

Volunteer at Life's End Pilot Project Training Plan

DAY ONE

What is a good death?

- Define the principles of palliative care
- Recognise indicators of the dying phase, including DVD featuring Herbie.
- Explore the individual nature of what may be perceived as a 'good death'.

Defining spirituality in the context of end of life care

- To enable participants to recognise the diverse nature of spirituality.
- To have an appreciation of what spirituality means to us as an individual.
- To identify ways in which spiritual care can be provided in a way which recognises and meets individual needs.

DAY TWO

Communication skills

- To identify effective communication skills.
- To recognise barriers to effective communication.
- To recognise the value of empathy and how it can be used to support patients and their families.
- To use effective communication skills and strategies for dealing with emotion such as distress and anger.
- To use communication skills to enable you to gain an understanding of the patient and family wishes and what is important to them.

Dementia – Worries and Concerns

Culture and diversity

- To define what is meant by culture & diversity in its broadest sense.
- To increase awareness of cultural aspects of death and dying.

DAY THREE

The role of the volunteer at life's end: Practicalities and resources

- Practical arrangements: sessions, homes, expectations of the role of volunteer, maintaining health and safety.
- What do I do during my 'session?'
- Resource Kit

After death: What happens next?

- To enable volunteers to have greater insight into what happens after a death.
- To have awareness of the procedures that will be followed after a death.

- To have greater awareness of other sources of support for bereaved relatives.
- The role of the volunteer immediately after death.

Looking after yourself

- Recognising the potential gains and burdens through your role as a VALE volunteer.
- Recognising signs of distress, anxiety and stress in ourselves.
- Strategies for maintaining safe and healthy volunteering.

Free text comments reflecting on the 3 day the VALE training programme

I feel the training has prepared me well for my new role

I had no idea what would happen but this training has helped me

It feels that it has but I don't actually know until I start in my role

I felt the 'communication' aspect of the course was excellent and would also really assist up and coming 'ward assistants'

I believe that the training has been useful in re=acquainting me with things that I have received previous training on and have had past experience in. My expectation is that in most cases patients will be far more 'end-stage' than the training suggests (rightly or wrongly) and in most cases be alone, without anyone to be with them in their final hours

As the new role is a new experience, I hope I am prepared. More time needed on dementia

I feel this training has given me more insight into my new role. As there has been lots of opportunities to discuss very sensitive topics, in depth and most questions have been answered.

I feel it has prepared me well but until I am in a situation, I will be able to comment more

I understand what being with someone as they die might be like

I am aware of emotions from being at someone's death, both of family and what it brings to the surface in oneself

I hope I can be a comfort to a person dying. I have witnessed some very traumatic deaths

To be with a dying patient and caring for him/her is a privilege. As strong emotions may become apparent and can be very challenging and powerful deciding and isolating individuals from family and friends can be very distressing.

Impossible to say as each one is different. The film gave some insight, as has my previous experience.

Having had previous experience of this, I do not anticipate any situations arising where I would feel that I was 'out of my depth'. However I appreciate that it is impossible to predict how every scenario will play out and I am confident that I will be able to draw on aspects of the training as required, should any unexpected situations arise

I feel I would have more confidence on being in this situation and handle it better

Agree slightly more than 'neither' as the physical manifestations of dying were described only after the film about Herbie was shown

Once I experience this I would be able to tell you

I would like more training on ....

Dementia, because I haven't experienced being with a person who has dementia

What happens during the dying phase? (physically)

Dealing with dementia

Defining spirituality in the context of end of life care (Helen Newman) as I found this particularly interesting. Also culture and diversity needs to be allocated more time. The subject was well covered but was just a bit rushed due to time commitments

I would prefer to come back to this after experiencing the 'new role'

Dementia, Parkinsons Disease, Alzheimers as I felt this was rushed as we were overun with time. Not sure about any further training at the moment but I am sure there will be in the future

Dementia (session had to be cut short due to time)

When we are out in the field undertaking our part in 'life's end' there could, I'm sure, be aspects which become apparent insight would be adventagious and perhaps discussed at an informal meeting maybe on a quarterly basis?

Any other comments you would like to make?

Our day 2 programme - felt I needed more insight into dementia - only time to 'skate over' the aspects - we did get a hand out which is informative. The culturral talk by Angana had to be rushed on the last part but we can speak to Anjana if we have problems of a cultural nature. This morning (Tues) did feel we had a 'good do's and don'ts' session which made a clearer guide for us. Much is a sensible ruling for you and for them.

The course was excellent. Thank you for organising! Could we visit the homes involved?

The programme highlighted a lot of areas that were very useful, and I feel I have learned a lot especially on communication skills. Having an actor is a great idea! Culture & diversity has given me a better understanding of death and dying with dignity in a multiculture society acknowledging the individual needs and customs relating to their culture. Very good and well explained. Anjana was great at putting the message across.

My greatest feeling after the training is that as yet I can't answer the questionnaire in a very helpful way, because only experiencing the situations I may face will throw up areas where help is needed. However I did think it gave a useful base on which to build. In the 'communication' session a lot of time spent on communication with relatives to what extent is this part of our role? (This last point clearer after today's session).

Although not an issue for me personally I am aware that some members of the group have expressed some concerns about dealing with patients with dementia (or displaying this symptomatology). I feel that more time should perhaps be allocated to this subject and perhaps less emphasis be placed on dealing with complex family dynamics, which cannot be adequately made clear that there are significant limitations to what this training equips us to do, in this respect.

On completion of the course I feel really engaged with the role that lies ahead. I was enthusiastic at the start, this has increased. Quarterly meetings would be really helpful and help develop the project successfully.

Leaving a week between the first and subsequent training days was good, giving time for reflection. Showing the film about Herbie on the first day was also excellent as it made it clear what the VALE project is about.

Training has been very very helpful for me, as I came with an open eye.

A very useful exercise, role play very helpful