Championing end of life care

Case studies from the Yorkshire and the Humber Skills for Care and health authority end of life care training project for residential care managers and end of life care champions

March 2014

“we help workers who do a great job, do it better”
Championing end of life care. Case studies from the Yorkshire and the Humber Skills for Care and health authority end of life care training project for residential care managers and end of life care champions, March 2014
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Introduction
Some 500 residential care managers were trained in end of life care and nearly as many residential care workers were being developed as end of life care champions. This was to enable more people to die in their preferred place and to reduce hospital admissions.

Background
Skills for Care worked closely with the health authorities (originally the strategic health authority, subsequently Health Education Yorkshire and the Humber) in Yorkshire and the Humber. It developed 516 residential care managers’ knowledge in end of life care and established 489 more staff as end of life care champions. The project included partnership work with hospices, GPs, community matrons, the Yorkshire Ambulance Service, the NHS, local authority commissioners and the Care Quality Commission.

Aims
The aims of the project were to:
- raise awareness of the importance of end of life care for people in care homes
- help more people with advance care plans to die in their preferred place
- increase the number of people with an allocated keyworker
- reduce the number of hospital admissions.

What was done?
A comprehensive training programme of four days for managers and two days for champions was rolled out across Yorkshire and the Humber. The programme was based on End of Life Care Qualifications units 501 and 3048. The delivery included taught sessions and it assessed competence back at the workplace. Champions were identified by the manager at each care home as a member of staff who was already championing end of life care. The programme developed the knowledge of over 500 care home managers and enabled nearly as many other staff to become end of life champions. A resource guide was produced which was mapped to the Care Quality Commission standards, including end of life care strategy and quality markers. The guide gave useful tips for managers in how to deliver end of life care and links to useful end of life care tools. An e-learning package was promoted to further embed end of life care into the sector.

Impact
The impact of the overall end of life care programme has been measured by:
- comparing pre- and post-training questionnaires from residential establishments
- reviewing data on hospital admissions, which identifies the source of admissions.

The evaluation report from the project has been published at http://www.skillsforcare.org.uk/Get-involved/In-your-area.aspx

The project linked with existing local projects and shares best practice across the Yorkshire and Humber region.

Read on to find out how the managers and their end of life care champions at 15 homes made a difference.

For more information about what is happening to develop end of life care in Yorkshire and the Humber, contact the Skills for Care area office on 0113 241 0958 or northern@skillsforcare.org.uk.

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The Meadows – North East Lincolnshire
The Meadows is a residential care home for 39 older people with dementia. The manager, Sharon Long, has worked in social care for 24 years, and has been a manager for two. Caring for an aunt at the end of her life and seeing “what good care looked like” was the trigger for Sharon to become a care worker.

Before doing the end of life care programme Sharon had experience in working with people at the end of their life but did not have formal training or knowledge. “It was seen as a role by healthcare professionals, coming into the home and working with individuals, without discussing the work they were doing with care home staff,” says Sharon. The programme has helped to bridge that knowledge gap; it provided in-depth information on end of life care and explored the Liverpool Care Pathway in detail.

Outcomes
Back at the workplace Sharon has put a number of key actions into practice, including:
  - Sharing information about residents who are coming to the end of their lives with other residents, more openness has led to people feeling more involved and included.
  - Recognising the importance of residents’ and their families’ wishes regarding their end of life care. This is now documented in a ‘My Life’ folder for each person.
  - Introducing a system of recording what worked well and what could be improved, which has encouraged staff to share their thoughts and feelings following the death of someone. This has led to discussions about how they can improve their practice.
  - Implementing an audit tool to record information about each death, which includes information about:
    - the person’s diagnosis
    - place of death
    - whether the person was admitted to hospital
    - what the reason for that admission was
    - whether the person was on the palliative care register
    - whether an advance care plan was in place
    - were anticipatory drugs in place
    - did the person pass away on the Liverpool Care Pathway?
  - Updating the home’s end of life care policy.
  - Building on the existing positive relationship with healthcare professionals and being more confident and assertive with them to ensure the best service for residents.

Learning
Key learning points:
  - always include residents in plans for end of life care
  - maintain good relationships with external professionals
  - recognise that the home can provide excellent end of life care by ensuring all staff are trained and feel confident about their role.

Next steps
Sharon is determined to offer first class end of life care to the people who live in the Meadows. She plans to visit the local hospice to share ideas with the staff and find out what else she could be doing at the Meadows. Sharon has arranged for 11 of her care workers to undertake end of life care principles training at the local college. Sharon will talk to the
residents and their families about the end of life care programme, the need for it and what it aims to achieve. Sharon is keen to find out their views and if they think the service is improving.
Cumberworth Lodge – North Lincolnshire
Cumberworth Lodge is a residential care home for 26 older people. John Cresswell has worked in social care for over 27 years. He has been a manager for 15 years and has worked at Cumberworth Lodge for three years. Previously, John worked with people with learning disabilities. There are two end of life champions at Cumberworth Lodge: Deborah Colley is the Senior Carer who has attended the Skills for Care champions programme, and Karen Lofthouse who has a level 2 end of life qualification.

John and his team have been determined to provide high quality end of life care for some time. The programme has endorsed the existing high standard of their routine practice, whilst providing helpful information on the:
- purpose and benefits of the ‘Do not attempt cardiopulmonary resuscitation’ (DNACPR) process
- establishment of an end of life care local network.

Outcomes
End of life care activities at Cumberworth Lodge now include:
- Refining the process for debriefing staff following the death of a resident. This used to take place on an informal basis, but John is now aiming to support staff more formally.
- GPs completing all appropriate DNACPR forms in line with residents’ wishes; these are now routinely as part of their care plan.
- A greater emphasis upon end of life care training for the whole of the staff group
- exploring with residents and their families how to find out their wishes and preferences, alongside the existing person-centred planning training and the person-centred thinking tool.
- Developing specific assessment tools, e.g. the communication tool, which among other things looks at spiritual and psychological needs as well as pain management. This gives the team the advantage of quickly and effectively responding to a resident’s welfare. The communication tool, which has been developed by John and his two champions, can capture vital information about an individual in one place that can be easily shared with the whole team.
- Meetings now take place weekly to update everyone about an individual and a plan of care is agreed.

Next steps
John is keen for all staff to enhance their knowledge and skills around bereavement to help relatives and staff manage the grieving process better. Information about the end of life care programme has been shared with residents and their relatives. The team is aiming to redefine their goals and are looking forward to taking the standards of care they deliver to a much higher level.

A carer’s story from Cumberworth Lodge
Gillian, a carer, was supporting her mum, Molly, and her uncle, Dell. The pair had lived together for 95 years, were fiercely independent, very strong characters and were adamant that they wanted to stay in their own home. In all that time they had cared for and supported each other with no ‘outside’ help, except the support of their family.

Gillian wanted this for her mum and her uncle too, just so long as they were safe.
Molly
Molly’s health was deteriorating; she became immobile and was being cared for by her even then very elderly brother. Following an admission to hospital for pneumonia, unfortunately Molly was diagnosed with endometrial cancer. It was at this stage that the local GP instigated the support of a local domiciliary care team. Despite recurring chest and urinary infections, Molly and Dell managed to stay in their own home for a further 18 months.

However, during the winter of 2010 it became apparent that Molly needed care and support during the night too and, despite massive efforts by the home care service, the rurality of Molly and Dell’s house meant this was impossible.

It was at this stage that Gillian telephoned Cumberworth Lodge and, one week before Christmas, Molly and Dell moved in for a short period of respite care. On New Year’s Day Dell announced ‘I want to go home now, but she (referring to his sister Molly) can’t come, she’s too poorly’. Gillian and her son Will supported Dell to do this. Dell returned home and Will moved in with him; being more local it enabled Will to visit his grandma daily, too.

Molly continued to live at Cumberworth Lodge. However, by March 2011 and following a number of stays in hospital, she began to express how she had “had enough” and did not want to go into hospital anymore. It was at this stage, despite already receiving excellent support from the local GP, district nurses and Cumberworth Lodge, that Gillian believes the whole team came together to really make sure all of Molly’s wishes were accommodated.

Molly’s last days were pain free and comfortable, and she had her family with her at all times. Molly passed away at Cumberworth Lodge aged 96 in August 2011.

Dell
Following a series of slips and falls and his experiencing a number of minor strokes, Gillian was becoming more and more concerned for her uncle’s safety. She therefore arranged for Dell to have a short stay in Cumberworth Lodge. During this stay Dell was assessed by the occupational therapist to determine what support he would need back in his own home. However, given the number of strokes Dell had suffered, he was physically unable to carry out any of the tasks asked of him. Following a further chest infection and another stroke, the decision was made by the team (the GP, district nurse, Cumberworth Lodge and Gillian) that an unnecessary visit to hospital would be unbearable for Dell. A ‘Do not attempt cardiopulmonary resuscitation’ order was put in place; an end of life care plan was established.

Dell passed away at Cumberworth Lodge aged 99 in June 2012.

Outcomes
Gillian believes both her mum and her uncle received the care and support that they needed at exactly the right time, by the right people. She believes that they both had very peaceful deaths.
In her opinion this is due to the following:
- open and honest communication
- regular communication
• a mutual respect for all parties—GP, district nurse, including out-of-hours district nursing team, Cumberworth Lodge, the owner, the manager and all staff, Gillian and her family
• the commitment to deliver high quality care from each of these parties.

For Gillian what also helped was the practical support she received from Cumberworth Lodge, such as:
• people who cared, to talk to when she needed it
• space to be alone
• a place to ‘put your feet up’ and ‘catch a nap’
• opportunity to use the telephone when needed
• food and beverages
• information about ‘what to do’ following a death.

For Gillian what did not help throughout this process was:
• The ambiguity that surrounds the funding of placements: Molly received Continuing Healthcare funding; this led to no uncertainties for her care. Dell, however, was being assessed by the local authority for eligibility for funding. Gillian’s experience of this was a negative one.

Suggestions
To have had a ‘designated carer’s room’ with perhaps a bed, a toilet and shower, tea- and coffee-making facilities, would have made life for Gillian and her family a little easier during those final days spent with Molly and with Dell.

To have someone explain the ‘funding process’ to Gillian and her family would have been helpful and would have resulted in an emotional situation being less stressful.
Burntwood Hall – South Yorkshire

Burntwood Hall is a care home without nursing in Barnsley that specialises in supporting people with dementia. The home has places for 35 people in individual rooms plus two rooms for married couples.

Jane Davis is the home manager, she has been the home manager for 18 months and before that she was the senior care worker for five and a half years. Jane has worked within social care for over 20 years and has experience in a variety of settings including end of life care via domiciliary support services. She worked for a specialist end of life care community service in Wakefield.

Before Jane became the manager, if any resident’s circumstances changed and they needed end of life care they had either to go to hospital or be transferred to a nursing home. In Jane’s opinion this is unacceptable. Since becoming the manager she has concentrated on supporting and training the staff to enable them to deliver good quality end of life care.

Outcomes

- The programme gave managers a great deal of support. Being a manager is often a lonely job but being able to network with other managers and get the support from the end of life care team has been invaluable.
- The whole staff team have benefited from the learning via the manager and champion.
- Stronger working relationships have been developed with doctors, district nurses, paramedics, the end of life care team and other managers through the training.
- As a result of the training Burntwood has developed and implemented a traffic light system which lets staff know whether any resident’s circumstances have changed.
- As a result of the training the manager and the senior care workers now have the confidence and knowledge to challenge locum GPs or out of hours doctors and act as advocates for the residents.
- When making assessments Jane is more confident in discussing people’s preferences, ensuring that residents and their relatives are aware that they have a choice when the time comes.
- Families now have the choice to be involved in as much of the end of life care as they wish.
- The home now has the necessary medication ready for when it’s needed.
- Burntwood has started to discuss feelings about end of life care at the recruitment stage.
Willowpark Care Home – West Yorkshire
Willowpark care home provides nursing and residential care for 64 residents in Pontefract. The senior nurse and clinical lead of the nursing care team, Ann Wilding, has worked in health care for many years, having qualified as a registered nurse in 1982. Before completing the manager’s development programme, Ann had experience of caring for people at end of life but wanted to take the opportunity to refresh and be part of any training that could improve delivery of end of life care at the care home.

The programme has helped Ann to review legislation and introduce different models and tools. It has also improved communication between staff and relatives, leading to a more inclusive approach to residents and their families having a deeper conversation about the resident’s wishes at end of life and putting a more detailed advance care plan in place.

Outcomes
Ann has put in place a number of changes, including:

- More structures in place to monitor end of life care with a register of residents, similar to a traffic light system, to enable staff to be more aware of residents who require more care as they approach end of life.
- A ‘preferred priorities of care’ document is more embedded into the caring routine, with staff having a deeper understanding of the document.
- More detailed records of staff conversations with residents about their end of life care needs.
- Using more national awareness leaflets, e.g. “This is me” produced to support caring for people with dementia.
- The key worker role has been strengthened to support the resident and the family at end of life.
- Improved already good working relationships with GPs and external professionals.
- Improved access to national information and palliative care tools to support staff in caring for residents and supporting family members.
- End of life care information is more readily available to staff with noticeboards and folders of information.
- Use of the end of life care Yorkshire and Humber guide to prompt Ann and the staff to have good practices in place.
- Offering more opportunities for staff to share feelings about the loss of residents, so Ann feels more aware of how staff personally deal with this.

Learning
- Key workers play a key role in the inclusion of the resident with families in discussing and documenting end of life care.
- Usefulness of palliative care and dementia tools to support staff to take a holistic approach and develop best practice when delivering end of life care.
- Ann recognised that even though they delivered good end of life care there was room for improvement and as a result staff now feel more confident and informed.

Next steps
Ann is committed to delivering a high standard of end of life care in the care home, ensuring all tools that have been implemented remain in place. She will continue to look for end of life care training for all staff to ensure they remain knowledgeable and competent. It is intended
to support all staff in accessing the EICA e-learning end of life care modules which will support them in practice and improve knowledge in end of life care.
Parkfield House – West Yorkshire
Angela Ridley has been a care home manager since 2006, and has worked in her current role at Parkfield House Nursing Home for the last two years. Angela is the Registered Manager but also undertakes clinical shifts on a regular basis to ensure she knows the residents well and to maintain her clinical expertise. Parkfield House in Keighley has 24 residents. The end of life care champion there is Joanne Sharples (deputy manager) who spends 75% of her time in a clinical role.

Outcomes
Both Angela and Joanne attended the EoLC Care Home programme and really enjoyed the taught sessions, which made them reflect on and look carefully at practice in the home. They both felt by the end of the taught programme that they had much good practice already happening at Parkfield House but they identified areas for improvement, which they are now developing and further refining. Three key areas are:

- an end of life care register (with a red ‘star’ attached to the resident’s case notes identifying them simply and at a glance as being on this register)
- enhancing the advance care plan, adding in a section about discussion on the Liverpool Care Pathway (LCP) and the contact number for the palliative care team
- palliative care or memory boxes for the residents and family of those at end of life, including a leaflet to explain the LCP to families.

Angela has organised additional training for staff on end of life care and staff at the home are now also more confident. Angela is also encouraging staff to attend the network in Bradford alongside herself or her deputy, as she feels the network is beneficial in sharing concerns and sharing good practice.

Angela and Joanne both completed workbooks following the taught sessions (which they felt to be repetitive), were assessed in the workplace and achieved the L3 and L5 QCF units.

Angela reports that the EoLC Care Home programme really helped to validate that they were providing good end of life care and gave them the motivation and confidence to apply for a local area funded opportunity to achieve the Gold Standard Framework (GSF). Angela encouraged the owners of Parkfield House to provide the required 25% funding contribution to support achievement of the GSF.

Next steps
Parkfield House is now working towards the GSF and is building on the developments above as part of this. Angela feels that Parkfield will most certainly achieve the GSF and does not feel overawed at all by this last part of their journey towards excellence in end of life care. She is confident in her staff team and about the standard of care her residents and their families receive at the end of life.
The Lodge – Rotherham
Teena’s background was general nursing (including older people) and then she moved into GP practice nursing. Through that she established good contacts with residential and nursing settings for people with learning disabilities.

Teena began at The Lodge (part of Exemplar Care) as care manager and then in 2009 became the home manager. Six people with learning disabilities live there (people often come from school or family home and then live at The Lodge all their lives; residents’ ages range from early 20s to 50s). Teena’s previous experience of end of life care (EoLC) had been through her work in a GP surgery supporting people in the community. When last year one of the people living at the Lodge died, having been admitted to hospital, it brought home to Teena and the staff how much more they could do to enable the people living at The Lodge and their families to be prepared for and understand EoLC. With the preparation and planning they have now they feel they could definitely enable someone to be able to die peacefully and with dignity at The Lodge if that was their preferred place of death.

Learning
The home had previously been through the Gold Standards Framework (GSF) process but hadn’t really utilised the learning from that. Teena said that the EoLC training was great: they workers got more out of the two days manager’s training and the follow-up days than they did from all the GSF work they did. The training was made relevant to them in learning disability services and avoided focusing totally on older people’s care or regarding learning disabilities as ‘the same as dementia’.

There wasn’t anything they disliked apart from the hard work to complete the units!

The thing that stood out was the quality, experience and knowledge of the trainer and her ability to listen to issues The Lodge had experienced.

The home has initiated a number of changes since completing the training:
- A ‘learning audit’ of the death they experienced last year to see if things could have being improved for everyone involved.
- Gathering appropriate information and resources to support one of the young women who live at The Lodge, whose mother recently died.
- A workforce development audit of the staff to see what EoLC skills, experience and qualifications the team already has and how to develop people where necessary.
- Looking at how they can support the people who live at The Lodge, and staff, family and friends, when someone dies, and to look at the wider impact when a person dies who has been the family focus for many years.
- Starting the process of talking to the people who live at The Lodge and their families about their EoLC preferences and wishes.
- Providing information posters and signposting of information on noticeboards for the people who live at The Lodge and family, friends and staff.

The Lodge provides very specialist care and therefore there are always people waiting for a place to become available. When the person died last year one of the considerations was for the management to be very carefully aware that someone else moving into that person’s room too soon, or at all, would be challenging for all concerned.
**Next steps**
The intention is to continue the development that they have already started. Both the manager and the EoLC champion will be involved in the Rotherham network. They are also engaged with Rotherham workforce development section to access the local authority Bronze to Platinum training programme for EoIc.
Millfields – West Yorkshire
Millfields provides non-nursing care to 38 residents in Pontefract. The home manager is Nicky Silvester who is a qualified nurse and has a wealth of experience in both health and social care. Nicky is very passionate about providing good end of life care. The communication element of the programme stood out and has assisted Nicky to ensure the staff feel supported in talking to residents about their preferences and wishes at end of life.

All staff are committed to providing end of life care, with 15 staff in the process of completing level 3 in end of life care. Lisa Croome, senior care worker, is the end of life care champion at Millfields and has a level 3 qualification in end of life care.

Outcomes
Nicky has introduced a number of changes at Millfields following the manager’s programme:

- Introduced the preferred priorities of care document for all residents, detailing individual residents’ wishes, including their small personal requests such as wanting to always wear their rollers or lipstick.
- The preferred priorities of care document have also been added to the resident’s user guide which is also available to families giving the opportunity to read at leisure.
- Each resident now has an advance care plan in place, involving themselves, their family and staff.
- Introduction of a de-briefing session when a resident has died, to allow staff to share their thoughts and reflect on their practice, taking the learning for when further residents are at the end of life.
- Relationships are in place with district nurses and GPs. As the home is starting to care for more people when they are at the end of life, Nicky is committed to ensuring these relationships remain in place.
- Introduction of an end of life care information folder for all staff to access. This is to help in improving their knowledge and to support their achieving the level 3 qualification.
- Residents and families are more involved in the process of caring and staff feel more confident in having the end of life conversation with both the residents and families.

Key learning

- Nicky has taken the learning and knowledge gained from the programme as a real opportunity to implement and make changes to end of life care practices in the care home.
- Staff are starting to feel more confident about talking to residents and their families about their wishes at end of life.
- Relatives are more involved in the process of caring for residents, particularly those with dementia.

Next steps
Nicky is committed to providing good end of life care for the residents at Millfields, with a priority to embed all the documentation recording each resident’s personal requests even at the end of life. There is also commitment to maintain good working relationships with GPs and nurses and to support staff to achieve the level 3 end of life care qualification.
Elmwood Nursing Home – Leeds
Elmwood provides nursing care for 32 residents in Leeds. The home manager, Jenny Firth, has worked in health and social care for many years. Jenny is a registered nurse specialising in older people’s services and has a palliative care qualification (EMB 931 Caring for the dying). Marcilinas Mesina, senior sister at Elmwood, is the end of life care champion.

Jenny has a wealth of experience in caring for older people but took the opportunity of completing the manager’s programme, achieving the 501 unit to refresh her knowledge of end of life care. The programme has assisted Jenny to step back and reflect of the end of life care practices in the care home, to make changes and embed the good end of life care which is currently in place.

Outcomes
- Jenny is committed to ensuring that any local initiatives for end of life care are implemented at the care home.
- Following the training, Jenny now attends the Gold Standards Framework meeting at the local GP practice. This has improved the working relationships with the GPs and nursing staff; importantly, the care home is now treated as an equal when delivering end of life care to its residents.
- Jenny attends a regular meeting with the end of life care facilitator and hospice which allows for reflection on residents’ care and deaths, sharing learning and gaining advice for future care of residents.
- More regular reviews take place of residents who are on the end of life care register.
- Advance care plans and end of life care pathways are already in place; however, Jenny has enhanced the process by checking more thoroughly the quality and level of detail that is included in the plans.
- Normal management practice is to talk to staff during a resident’s end of life care, and after they have died. The workers also attend residents’ funerals and support family and friends after the death. Jenny has introduced sending a bereavement card to all families or friends.
- Following the training, Jenny attends the end of life care network in Leeds. She finds it very beneficial to meet other managers to share knowledge and best practice. It is also an opportunity to see and gain advice from the hospice, EoLC facilitator and speakers from the hospital.
- Jenny has introduced end of life care information onto the respect and dignity noticeboard that is available to all staff.
- Elmwood has a person-centred approach to how care is delivered, with all staff involved in the delivery. This will continue as a good and essential practice. Jenny also delivers a half-day end of life care course to all staff.

Key learning
- The training provided Jenny with an opportunity to reflect on the end of life care practices currently in place in the care home. Small changes to embed best practice will make a real impact on the care delivered.
Alba Rose – North Yorkshire
Alba Rose care home in Pickering, North Yorkshire, is home to 17 older people. Ann Barnes is the care manager and her deputy is Tiffany Hunt. Ann had already undertaken a specialist palliative care course, so Tiffany was encouraged to attend the EoLC manager and champion programme with a senior care worker, Marilyn, to strengthen both the expertise and the leadership team in end of life care within the home.

The owners and leadership team at Alba Rose firmly believe that it is a privilege to care for people at the end of their life and provide the best possible care and support for the person and their family at this time. The home already has excellent relationships with the local GPs, district nurses, and Macmillan and Marie Curie teams.

Outcomes
The manager and champion programme provided Tiffany and Marilyn with a deeper understanding of end of life care, increased their confidence and enabled the opportunity for their team at the home to reflect on the quality of all aspects of end of life care. Tiffany achieved the L3 and L5 unit and Marilyn achieved the L3 unit. They thoroughly enjoyed the group taught sessions and the sharing of ideas, but felt the workbooks to support the L3 and L5 units were repetitive (particularly when achieving both units).

The increased confidence from the programme enabled supporting and teaching less experienced members of the team to care for people at the end of their life. It has also enabled Tiffany to be more assertive, e.g. calling the out of hours GP service a second time when there seemed to be a delay, to ensure medication for pain relief was prescribed appropriately and in a timely manner.

Next steps
Ann or Tiffany attend the EoLC network in Scarborough (facilitated by a Skills for Care area officer and the specialist end of life link nurse team at Scarborough Hospice), again as an opportunity to learn about good practice and to share ideas. Following a session at the EoLC network on the e-learning for health resource (e-ELCA), Ann has registered herself for an account and intends to cascade and use this resource with other staff.
Richden Park Care Home – North Lincolnshire

Richden Park is a residential care home. Vanessa Miller is the Registered Manager. Vanessa has worked in social care for 2½ years, before that she was a practice Nurse and a district nurse for over 15 years. The champion there is Lydia Bean, who has worked in social care for approximately 18 months.

Both Vanessa and Lydia are passionate about improving the end of life experiences for the people living in their care home. Vanessa became the manager of Richden Park in February 2013. Having had some negative personal experience of how someone was cared for at the end of their life, Vanessa was determined to improve the quality of care delivered at Richden Park.

Vanessa and Lydia commenced the Yorkshire & Humber EoLC programme in January 2013 and both have successfully completed their work-based learning. During the training they particularly benefited from the conversations with the trainers and with the other candidates, and particularly from discussions about the Liverpool Care Pathway.

Challenges

Prior to being involved in the programme, some of the challenges encountered included:

- conversations with out-of-hours GP services who were reluctant to become involved in the care of residents and who were quick to admit people to the local hospital, even if this was against the individual’s wishes.
- difficult conversations with staff in the A&E department, who showed limited respect to any care staff accompanying residents on hospital admission. Hospital staff would telephone Vanessa for information about an individual rather than speak to the care staff and/or read information on the individual’s hospital passport.

Outcomes

As a result of being part of the programme, and part of the network, these issues are now being addressed very actively. This is because they are challenges being experienced by most managers and therefore can be addressed as part of a larger group. Also as a result of the programme, there has been an increase in the number of completed advance care plans for individuals. Discussions are held regularly with GPs, residents and their families about the completion of “Do not attempt cardiopulmonary resuscitation” (DNACPR) orders by GPs. As well as being involved in the local EoLC network, Vanessa is involved in the managers and matrons meeting at the local hospital.

As the EoLC champion for Richden Park, Lydia initially led the conversations with residents about their wishes for end of life care. This led to an increase in her confidence which has had a positive effect on the other staff who have also had opportunities to attend end of life care training and who now feel more confident and competent about having those conversations with individuals and their families.

There is now a training matrix in place and it includes completion of qualifications and attendance at study days and workshops for all staff. Regular meetings take place with the Marie Curie and Macmillan Nurse teams. And support mechanisms are now in place to enable each member of staff to discuss, one-to-one or in groups, their feelings and reflections on the care being given.
Future plans

- To ensure there is high quality end of life care at Richden Park.
- All staff are to achieve a level 3 in end of life care.
- To make sure the wishes of residents at Richden Park are followed.
- To make sure families and friends of residents always feel included.
- Changes to the environment are planned for Richden Park too. A sensory garden is to be developed. Rooms are also being created to enable families to stay overnight when they wish.
Green Acres care home – North Lincolnshire
Siobhan Worthing (Registered Manager) and Jean Bellamy (EoLC Champion) have taken part in the Yorkshire and the Humber End of Life Care Programme. Both have worked at Green Acres for a considerable number of years and are extremely passionate about the 37 people who reside at Green Acres, and would like to share a couple of stories.

George
Over the past 12 months a 92 year old man (George) with a learning disability, a chap who had lived at the home for 15 years with no immediate family around him, had started to deteriorate. He became less interested in things around him, he became reluctant to eat, and at times he stopped talking with staff. The local GP was unwilling to diagnose that this man was nearing the end of his life and so, when George developed a chest infection over a weekend and with no advance decision documents such as Preferred Priorities of Care or DNACPR in place, he had to be admitted to hospital. As soon as he arrived, George expressed a wish to return home, he repeated this wish constantly and when it became obvious he was not being listened to he began to refuse any food at all and would only talk with staff from the care home, refusing to communicate with the hospital staff. Once it became clear that George was not responding to treatment, the manager and the staff at Green Acres asked if he could return home. However given that Green Acres is a residential home and not a nursing home, hospital staff were reluctant to make the decision to discharge George back to his home. In the meantime George was declining rapidly. Following a number of hasty calls and meetings with the Discharge Liaison Nurse, the social worker and the district nurse, George and the registered manager were finally told that he could return home.

George returned to Green Acres with a DNACPR in place and a letter stating that he would not have to return to hospital. George lived for a further three weeks over Christmas. In that time he would eat only chocolate and drink cherryade, he watched his favourite films and TV programmes and the staff at Green Acres never left his side.

Jack
Jack, a fit and active man in his 90s, suddenly became unwell. The GP diagnosed a urine infection and prescribed some antibiotics. Two days later Jack was continuing to decline and the GP felt that he may have had a stroke and so Jack was admitted to hospital. Once in hospital and following a diagnosis, Jack, his son and the care home wanted him to return home. However, the hospital staff felt that Jack was deteriorating so rapidly that he ought to be discharged to a nursing home rather than the care home. Following meetings with Jack’s family, the discharge liaison team and the district nurses, it was eventually agreed that Jack could return to the care home.
When the ambulance brought jack back, he said ‘Oh I am so glad to be back.’ Jack lived for a further five weeks at Green Acres.
Outcomes

- Both Siobhan and Jean believe that being part of the Y&H EoLC programme has given them the confidence and the determination to be able to speak up to doctors and healthcare staff on behalf of the people they are delivering care to much more than they would before.
- All 35 staff, including ancillary staff, the handyman and chef at Green Acres, have now undertaken EoLC training.
- Residents and families are all fully aware of the training that the staff have undertaken.
**Chapel Garth care home without nursing and dementia care – Doncaster**

**Background**
Elaine Lindsay is the care home Manager at Chapel Garth. Elaine has worked in social care for 23 years, having started working in the laundry in the care homes, then moving to administration, then became deputy manager and finally home manager. Elaine has been in her current post for 11 years.

Daniella is the home’s end of life care (EoLC) champion. She enjoys the practical side of the job and is interested in EoLC. Daniella has worked in social care as a team leader for 16 years. Daniella’s knowledge and experience of EoLC is good and she completed a basic one-day training to start with when it first began. Doncaster local authority offers free training, so other staff have accessed this. The new training has given Danielle more knowledge and confidence in dealing with EoLC, meaning that more residents can die in the home rather than in hospital, this proving a more comfortable environment for them.

**Outcomes**
The manager felt that the positive side of the training has given her knowledge and confidence about managing EoLC. The training was also good because it allowed her to talk with other managers about the difficulties they all felt in EoLC, such as trying to communicate effectively with GPs and family.

Although the manager was informed that she would be able to discuss what she learned in further depth with her assessor, there were difficulties in meeting with the training provider. The manager felt that she would have learned more if she had been able to discuss the scenarios with the assessors. Daniella has had the same issue and stated that there is a danger that others may end up losing interest because of this. The thing that stood out most about the training for the manager was that the trainers themselves were very good as they had previously dealt with EoLC in Sheffield. They knew about the issues surrounding this type of care, such as families not wanting to discuss matters surrounding death so care workers feel ‘in the dark’ as to what residents want.

Since the training, the manager has implemented a process in which families are always asked about what residents would like should anything happen to them. For example, they would discuss whether the resident would prefer to die in the home or in hospital. There are key workers in place and they each have a named senior worker. The residents’ wishes are always respected even though it is difficult with a large number of residents having dementia. The staff and GPs would only do the decision-making if there are no family members or friends to be contacted. The training has taught care workers to respect residents’ wishes more.

The manager felt that being involved in her local network has allowed her to realise that other managers are going through the same issues in relation to EoLC.

The manager felt that relationships with GPs were good when the residents go and visit them, but some GPs are reluctant to come and provide care in the home. There are no nurses working at the care home so they are reliant on GPs and support from district nurses. There are still problems with the completion of DNACPRs forms. The manager felt
that professionals need to consider the resident’s background when it comes to providing care, e.g. many residents suffer from dementia and are unable to express their wishes.

The manager felt that the team are better at communicating with relatives and friends of the residents now. In the time leading up to one of the home’s most recent deaths, the care workers allowed a separate lounge for the resident and his family to sit in so they could have some peace and private time together.

**Future plans**
The manager intends to set up an EoLC committee within the care home to support staff and so they can discuss as a team what they can learn from the experience or what they could have done differently. The committee could also be an emotional release for the staff as they are likely to feel grief for the resident they were providing care for. More staff briefings on EoLC will allow all staff to be involved and share their thoughts and feelings. The manager is also going to contact one of the GPs who seems interested in EoLC to see if they want to be or can be more involved with what we are doing.

Feedback the manager has received from relatives and families shows that the death of a loved one is much easier to deal with if the family feels their relative had a ‘good death’.

The manager felt it is important for care homes and training providers to work together as there could be a knock-on effect if the Doncaster EoLC network has low attendance.
Abbey Lea care home – Selby
Abbey Lea is a residential care home in Selby providing care for 23 older people with dementia. Beverley Emmett is the registered manager who has worked there for 14 years and worked in social care for 23 years. Beverley has achieved NVQ level 4 and her team of staff are very committed to providing quality care to all their residents. The care home has a good relation with the local GP practices and district nursing teams.

Both Beverley and Carol, the home’s EoLC champion, have been involved in the end of life care programme and are committed to providing good end of life care as hospital is not always the best place for a resident to die. The majority of the 33 staff have completed or are completing a social care qualification and some staff have undertaken end of life care training.

Since completing the training session the manager has taken the opportunity to review current practices and documentation within the home.

Outcomes
- The manager is more aware of the support that can be accessed from the local hospice in York and has visited on their open day.
- The manager has improved the end of life care plan, including more detail of resident wishes of preferred music or clothes, family involvement and bereavement services. This has been completed in consultation with the GP.
- The manager feels more confident in talking to residents and their relatives about their wishes at end of life.
- The manager has disseminated the information to all staff in the care home who also feel confident that they have all the relevant information about the resident when talking to relatives or professionals.
- The manager continues to encourage staff to reflective on their practices when a resident has died and continues to encourage staff to support each other.

Future plans
The manager may consider adding end of life care wishes to the preadmission questionnaire and to the information that is given to new residents and their families on arrival into the home. This ensures that the information about their total care is discussed at an early stage.

The care home has seen a decrease in hospital admissions over the past three years. This positive progress may be the result of a low turnover of staff, good relationship with the GP, and the manager and staff being totally committed to the residents’ wishes that the care home be understood to be their home. The manager will continue to monitor the progress.
Morrell House care home – York
Morrell House is a care home in York providing dementia care for 29 older people. Anne Macpherson is the registered manager who has been in post for the past 12 months and has 22 years experience of working in social care. Anne has a level 4 care qualification and has been involved in the end of life care programme, completing the champion’s course. Anne is totally committed to improving care to the residents.

The care home employs 39 staff with the majority having achieved a level 2 or level 3 qualification. The home has a good relationship with the GP who visits the care home on a regular basis. Also, the home is supported by district nursing staff who support access to medication for residents at the end of life. Accessing equipment can sometimes be a challenge.

Outcomes/future
- The manager has added end of life care to the pre-admission documentation so that individuals or their families are able to express their wishes at an early stage.
- The manager is looking to add end of life care wishes and preferences to the care planning process. End of life care would be discussed and become part of the whole care delivered.
- Staff have started to access end of life care training but feel they would benefit from more basic awareness regarding advance care planning and having the conversation with residents.
- The care home has seen a reduction in hospital admissions which may be due to:
  - no staff leaving in the past 12 months resulting in a consistent delivery of care
  - staff being also more aware of professional support and having confidence to contact the GP
  - the district nursing service being very good at offering support and advice to the staff in the care home
  - the manager being committed to providing quality care and supporting staff when a resident needs a higher level of care.