Supporting people in the advanced stages of dementia

A case study-based manager's guide to good practice in learning and development for social care workers supporting people in the advanced stages of dementia

May 2013

"we help create a trained and qualified workforce"

skillsforcare

Preface

Sharon Allen
Chief Executive Officer
Skills for Care

Dear Colleagues

I am very pleased to introduce the latest Skills for Care product, which focus on developing the skills of the social care workforce that support people with dementia.

This guide has been commissioned by the Department of Health. It is aimed at leaders and managers working in services that are providing care and support to people in the advanced stages of dementia. The guide supports leaders and managers in developing their workforces to enable them to provide the highest quality of care in these services.

The good practice guide has been compiled by Skills for Care, working closely with social care employers and key partners across England. The guide is developed for our sector, by our sector so we are confident that the information, advice and guidance contained within the guide will support the development of your team.

The guide considers how reminiscence can be used by the workforce to support people with dementia. It provides examples of meaningful activity for the workforce to use to engage people who have dementia.

It also highlights dementia-specific qualifications, which can be used to develop the knowledge and skills of your team, what support is available from other professionals to help your team, as well as many other useful areas.

Throughout the guide there are a number of case studies and examples, as well as links to further resources to support you and your organisation.

We very much hope the guide is effective in supporting you in your role. We welcome your feedback and comments on this guide, so please feel free to get in touch with the team at Skills for Care or contact us via email at: info@skillsforcare.org.uk

Contents

Recruiting staff for values and moving away from a task-driven culture 1.

Supporting staff to enable meaningful activity for people with dementia 6.

Reminiscence and staff development 13.

Culture to support person-centred approach 16.

Innovative use of information technology to help staff to support people with dementia 19.

Reflective Learning and Supervision 23.

Promoting Dignity in the Advanced Stages of Dementia 26.

End of Life Care (EoLC) for people in the advanced stages of dementia 29.

Qualification Progression Routes to support the workforce 34.

Working with other health and social care professionals 36.

Useful resources 39.

Acknowledgements

Skills for Care would like to thank the organisations that have worked with us to produce this guide

- Housing 21
- Hartford Care
- Northhill Care Home
- Leicestershire County Council
- Anchor
- Certitude
- Jewish Care
- Registered Nursing Homes Association and The Partnership in Care

Thank you.

Recruiting staff for values and moving away from a task-driven culture

Five top tips for other managers:

1. If possible, involve people with dementia and/or those closest to them in describing the important characteristics in the people who will be supporting them. This can be added as desirable characteristics to the person specification

2. Think beyond skills and competencies to the person's nature and approach, their interests, shared histories and values

3. If possible, involve family or friends of people with dementia in the selection process such as having a second stage to recruitment where the candidate meets them

4. Following selection, tailor the induction to the people with dementia who they will be supporting as well as basic skills and Common Induction Standards

5. Select people who can demonstrate they are reflective and adaptable and will be able to quickly change their approach, as support needs change.

The importance of the values and attitudes held by the workforce that provides support or care to people is recognised as being critical to high quality care and support. Certitude provides support to people with Learning Disabilities and Mental Health needs across London. Over a number of years they have taken a range of approaches to ensuring that the organisation, and more importantly the staff working within, are creating a culture of person-centred working and continuous learning. The aim is to work in a way which tailors support to each person, maximising choice and control. Creating the cultural and practical shifts within an organisation to ensure that staff all contribute to working in this way, stems from taking whole organisation action, recruitment, induction and continued learning within teams, supported by senior management and all departments.

One example of an area of provision is an accommodation-based outreach service to over 50 people with a learning disability in one borough who live in their own homes, often sharing with others who also have a learning disability.

As people have aged, support needs have changed and for a few people dementia has become a real issue in terms of its impact on the support required to maintain the life they want and enjoy. Using a personalised approach to recruitment, support planning and review has enabled the service to adapt around the individual in light of changing needs. Multi-disciplinary working has been key with planning and decision-making remaining as close to each person as possible, with the support of staff, local authority, health teams, family and friends. A variety of approaches to continuing to support people have been the main outcomes, with some people moving into a care home setting. One person in particular was adamant that this would not work for him, and he wanted to be supported to remain at home.

This case study considers an approach to recruitment which ensures an individual's wishes and needs are kept to the fore, and they are involved at each stage of the recruitment process, from considering the attributes and characteristics staff need to have, to making the choices of who supports them. Paul's story illustrates how this can lead to positive outcomes for an individual with advancing dementia.

Over the last few years Certitude has co-produced an approach to recruitment, which moves away from simply assessing the skills and experience of potential support worker roles. Recruitment has shifted from an organisational and Human Resources-led process, to one that starts with the person or people and the existing team around them. When a vacancy or need for a new staff member is identified, managers include the people they support in describing the characteristics, interests as well as skills and strengths they desire from the new staff member. This informs both the job description person specification and advert to recruit the new employee.

In recent years it has become a more widely held view that staff need to have the right skills to provide good care and support, that can be taught, as well as the important characteristics that make a great care worker including behaviours, approaches and characteristics, which represent the values they hold. Values themselves inform human behaviour but can be harder to measure. They can, in part, be captured through personality profiling, and are mostly experienced through the personal interactions between the staff and the worker. These interactions and relationships were key to getting the right support for someone who had a learning disability and experiencing advancing dementia.

Case study example
Paul's story

Paul has lived for most of his adult life in his own flat, in a property shared with a number of other people with learning disabilities. An outreach team provided direct support for up to five hours a week. A few years ago it became clear that Paul's memory and ability to maintain his independence were deteriorating, and he was subsequently diagnosed with dementia. Paul's wishes were discussed with him from the start and he made it clear to staff that he wanted to remain at home, rather than being moved into a care home or other setting. He was also supported to discuss this with the friends he was living with. However, the five hours support he was getting at the time was not sufficient to keep him safe and well. Therefore, working jointly with health professionals and commissioners, the manager represented Paul's views and it was agreed that a full-time support team should be recruited to support him in his own home. The other residents he shared with, would continue to receive outreach support. This flexible approach to commissioning and workforce design, as well the process by which staff were recruited and trained, was key to the good outcome achieved for the individual.

Initially, a team of agency staff was used to cover the increased support, that went through both an interview process and training. But it became clear that he needed a consistent team with some specific attributes. As Paul's dementia advanced and affected both his physical and cognitive functioning, the team that had known him for a number of years worked with him to draw up the profile of who could best support him. This matching staff process involved creating a profile based on Paul's wishes and needs, including the characteristics, interests and hobbies, as well as the skills of the staff he wanted to support him.

The key attributes which mattered to Paul were:

- A general connection – having staff who would share and understand his history and relate to the popular culture he connected with going back to when he was younger
- People who placed utmost value on communication and their relationship with the individual, who would talk to him and reflect on what was going on around, whether or not he responded
- People who valued his independence and would be willing to spend much longer on activities such as eating and not rush him, or take over to support him too soon.
- People who got on with him as a person and would positively represent him to others, such as medical staff, when he needed to be admitted to hospital
- People who placed a value on this other friendships and relationships and supported him to maintain those.

Those who knew him well, also identified other attributes, which would be essential, based on a strong value base of seeing the person, rather than their health or support needs. The key attributes were identified as a caring and gentle approach, being able to respond naturally to Paul's changing needs, and focus on supporting him with activities such as personal care with dignity and without judgement. Adaptability and potential to change was also seen as key attribute. The advancing dementia meant that constant reflection and adapting of Paul's support was necessary, so the team had to regularly communicate, share changes and quickly adapt approaches to ensure consistency of support.

The recruitment process involved potential staff being invited to meet Paul in his home setting, to spend time with him, other support staff as well as his friends who had known him for many years. Those who knew him well spent time observing, assessing and reflecting on the interactions between the candidates and Paul, and how both parties responded. Not only was Paul able to give his views, but also candidates were able to get to know what the role would entail and consider their own perspectives. This process was clear and transparent and explained to candidates.

To summarise, the process to find the right team involved:

- Creating matching staff profiles for the person and the candidates
- Comparing these both on paper and during the interview process
- Carrying out a competency-based interview
- Involving the person in the recruitment decision by observing time spent with them, the interactions offered, and the responses of the person to the potential support staff
- Involving others around him such as other people living there, and staff or family who knew him well
- Tailoring the induction around the person's individual support needs

Paul now has a team of three staff who support him 24-hours a day. He continues to do the things that matter to him to have a good quality of life, as well as stay in his own home, which was the outcome he wanted. He maintains close friendships with the other people he lives with.

Some of the key implications for workforce issues included staff development. Managers received training and worked closely with HR to implement a clear, fair and tailored recruitment process. The staff supporting the individual received personalised inductions and ongoing learning interventions are the person's needs changed. Close working with health professionals and staff providing induction to hospital and other health staff was also essential.

The key learning to share with other social care employers included:

- Recruitment needs to put the person at the heart of the process and look wider than just skills to get the right staff
- Observing interactions between potential staff and individuals can indicate how they communicate, how they relate to each other and how they will engage the person during support
- Recruitment is only the start to getting it right. Continual input into learning and listening to changing needs and supported staff to adapt with them is essential.
- With advancing dementia one of the key characteristics needed in staff was the ability to observe, work together, learn and adapt.
- Learning and development for staff is important but keeping support person-centred is crucial
- Develop strong team communication and support.

Supporting staff to enable meaningful activity for people with dementia

Five top tips for other managers:

1. Get to know the person well, through the development of a life story. This is fundamental to providing activity and occupation that is meaningful to the person.
2. Activity and activities do not have to be complicated and structured; sometimes the most positive outcomes and experiences result from being spontaneous.
3. A sense of satisfaction and achievement for the person living with dementia should be the focus for the end result and not solely the production of an end product.
4. Share what works with each other. If people have similar interests to the person, then match them up. They are more likely to enjoy the connection and experience.
5. Be flexible in your approach and be vigilant to any changes in what the person is communicating, both verbally and with their body language. You may need to adapt your approach or change what you are doing to maintain the person's interest.

Anchor has a dedicated dementia specialist team to support all employees and activity coordinators to facilitate individual and group activity and occupation for individuals to live well with dementia.

A person living with dementia is just that: a person first and living. Often for the person living with dementia, their main interaction with others is focused on personal care tasks. Whilst these are essential, a person is more than a group of tasks and should not only be defined by what they need. Our challenge is to ensure each person lives well. This can be achieved by really getting to know the person through the development of a life story and focusing on the person's abilities now, what they were and what they are interested in.

Activity and meaningful occupation are essential components of living well.

For many individuals in the earlier stages of their illness, they may still be able to complete an activity-based task, but may need some help in solving problems. As the person's dementia progresses this may change, and you may find that there is more interest in observing and listening rather than just completing tasks.

By getting to know the individual, you can start to identify the person's interests and preferred lifestyle choices. From this you can develop person-centred activities that will more likely relate to interests that were important to the person in the past or perceived by them as important now.

Through activities and remaining occupied, you can help the person maintain their skills and feel better about themselves through providing a sense of achievement. An example of this is when Mari moved into the care home from a large house. At first she was very unsettled, often calling out to those around her 'to get out of my house'. Through conversations it was discovered that Mari's house had been her pride and joy. The housekeepers in the care home 'befriended' Mari and she now spends most of her days working alongside them. On a recent visit from her GP, Mari informed him she was too busy to see him as she was working. The housekeeper she was working with suggested it would be a good time for a break. Mari saw her GP and then returned to work. Today Mari is occupied most days doing something she enjoys and spends time with a small group of people she likes and calls her friends.

Another example is Zeneca who was very quiet and withdrawn until she was put in charge of collecting the care home's chickens' eggs and looking after the rabbits. Through conversations it was discovered that Mari had lived on a farm in France for many years where she looked after animals, so she felt comfortable in this role.

It is also worth being aware that things may change over time. When he first entered the care home Patrick was settled but over a period of time Patrick's behaviour changed. He started to take furniture apart or turn it over. From conversations and developing his life story the team discovered his job had been a handyman and was always interested in fixing things. The handyman supported Patrick and they successfully completed tasks together and he is much happier.

Carrying out uncomplicated tasks can help the person feel better by giving them a sense of self-worth and achievement. The person may become more alert and interested in what is going on around them. Elsa had lived in the care home for some time. As her abilities reduced, the team struggled to find things that interested her. They did notice she seemed to respond positively to hymns that were played by another person. A member of team put together some very familiar hymns for Elsa, who started to respond when they were playing by singing and talking about her Sunday school memories. This provided a means of connecting with Elsa when she was relaxed and responsive.

Some types of activity can help the person you're caring for to express their feelings.

- Creative writing – use objects that are familiar to the person or group you are with, such as terry towelling nappies, jars of nuts and bolts or sewing box, and talk about the items. You can write down the different responses on each line and create a poem about each object which can be compiled into a book.
- Shoe shine kit– shoe polishing is a great activity to start conversations for everyone taking part, either as an observer or a polisher.
- Personal activity bags – these can be developed in a similar way to a memory box and be personalised with things that are relevant to the individual. The advantage of a bag is it can be carried around and looked at when the person desires.
- Photograph and picture box, filled with either personal or general pictures – this provides the opportunity to either recall memories or introduce new topics of conversation.
- Odd sock basket – sorting, matching items. Any fabric items can be used.

Boredom and frustration are common causes of behaviour that we may find challenging in people with dementia. If the person is occupied and stimulated, the behaviour that you find most challenging may lessen or even stop altogether.

Dan became bored very quickly and this often escalated into perceived difficult behaviours. One team member spent time talking and listening to Dan and found out he loved boats. They spent time together finding pictures of boats and cutting these out. Dan enjoyed this. The team member then introduced envelopes. Dan now spends his time looking at his pictures and sorting them into the envelopes.

Discovering new ways to stimulate the person can be satisfying, and may enable staff to think differently about their caring role. An example of this involves Margaret who used to be a professional dancer and entertainer. A member of her support team arranged a visit to a locally run 'Music to Movement' class. Margaret was performing the foxtrot in minutes and had a fantastic time making new friends and relaxing in a different environment. Both now attend regularly.

In addition to supporting meaningful activity within the care environment, Anchor encourages various activities in the community. Some examples of this are given below. The case studies may provide some suggestions to you and your team about alternative activities for people with dementia.

Case study examples

Greta has Alzheimer's disease and has lived in the care home for over two years and uses a wheelchair. Greta was born in Germany and came to live in the UK in 1955. Since moving in she has always been a very reserved and private person and it takes a great deal of time for Greta to gain anyone's trust. Greta tends to spend much of her time in her room alone. The activity coordinator started to spend more time with Greta and their relationship grew and they become close. Greta confided that she was not lonely but felt she had nothing in common with the other residents. Through time and conversation a mutual love of art was discovered. The activity coordinator investigated the local Art Gallery and found they had paintings on display by Greta's favourite artist. A visit was arranged that involved using the bus service crossing the town centre and touring the Gallery. Greta had a fabulous time and now they make monthly visits together. In addition to this, Greta now has art books to look at and is more likely to talk to others about her love of art and Gallery visits.

Joan is a younger resident in the care home, is very reserved and avoids any group situations. Through conversations and the development of a life story, it was very apparent that Joan had a very active social life involving many friends. Therefore, once a week it was arranged for Joan, along with a care worker, to visit a local Italian restaurant within walking distance of the care home for elevenses' coffee and cake. Joan looks forward to these visits, and reminisces about her life before moving into the care home.

Corrine was very withdrawn and often angry towards others around her, so people tended to avoid her. Through very sensitive discussions, the care team found out that Corrine had been a member of a Ramblers Club. A member of the care team was also a keen walker and started spending more time with Corrine discussing different walks and different destinations. Twice a week they both go for a walk with a pre-planned destination. Although Corrine needs support to walk and is often silent during this time, she always appears happier on her return. There have been no angry outbursts since the walks started.

Joseph moved into the care home from hospital following the death of his wife. Joseph was understandably very confused and withdrawn. Through gentle conversation, it was discovered Joseph was not only interested in natural history but also extremely knowledgeable. One of the care team members was also very interested in this and they now visit the local Natural History Museum together every month and stop off for a drink on the way home. Joseph is being supported and working through his grief, is happier and less confused.

David and Lois are married and live together in the care home; both have dementia. David was Lois's carer for a number of years before moving in. During conversations it was discovered that David felt lost without his caring role and acknowledged that he was unable to help his wife in the same way due to his health status. As a result, he was avoiding spending time with Lois. Together with a team member they talked about what he could do rather than not do, so now visits a local supermarket adjacent to the care home, with a care worker, where he buys a dessert or chocolate bar for Lois everyday. He then spends time with Lois helping her enjoy this afternoon treat. David now feels he is actively involved in Lois's care and their relationship is closer again.

Barry moved into the care home over a year ago, was very cheerful and sociable and preferring the company of other men. His love was sport, but stated 'that was all over now'. The activity coordinator contacted another local care home to investigate what male-orientated activities they offered. Through conversations with Barry and the other care home, an evening with another male resident Alan was arranged at a bowling alley. They then went on to the local pub and returned back to their care homes full of information about the evening's events. Barry referred to Alan as his new mate. They now visit each other and watch football together.

Peter has lived at the care home and has very limited speech. Others often avoided him as he appeared very angry, usually clenching his fists close to his chest and seemed to be punching his arms up and down. The activity coordinator, with the care team spent more time with Peter to develop his life story. Peter has no visitors so they used a variety of approaches including books with pictures, communication cards and building on key words Peter used. It was discovered he had been a long distance lorry driver for over 40 years and his clenched fists were his driving actions.

The activity coordinator contacted a local lorry yard and explained the situation and a visit was arranged. As Peter arrived he smiled, put on the hard hat and high visibility jacket and walked around unsupported with the yard manager who responded positively and appropriately.

Peter continues to drive his truck in his chair and those around him now understand what he is doing.

Colin and his wife Jenny had moved into the care home together over three years ago, but Jenny recently died. Since his wife's death Colin, who has dementia, has become withdrawn and very unhappy. The team understood Colin was grieving and provided additional time and opportunities to talk about Jenny and their life together. During one conversation Colin started to talk about his time in the RAF and through gentle encouragement it was discovered that he had been a mosquito pilot. The activities coordinator made some investigations and found an air museum some distance away that had a mosquito on display. Photographs were used and shown to Colin and he became very excited, since it was exactly the same plane he had flown. The activity coordinator contacted Colin's family and explained how enthusiastic and animated Colin had become through this discovery. The family stated 'do whatever it takes' to get Coin there. The activity coordinator contacted the air museum and arranged a visit. On arrival Colin expressed his delight, and talked to the museum staff with great enthusiasm and explained complicated mechanics and technical specifications of the aircraft. On return to the care home later in the day Colin continued to discuss his day and much to his family's surprise continued to talk about his RAF's days with clarity.

Etta was 92 years old when she moved into the care home as an emergency admission following a house fire caused by leaving a cigarette unsupervised. Etta was understandably distressed and very confused. Over the following weeks, through conversation and life story work it was discovered she had in her youth been a very competitive swimmer, winning cups and awards. As time passed and relationships grew, a team member who loves swimming suggested to Etta that she accompany her to the local swimming baths. Etta was delighted as she had not swum for 60 years. On arrival and entering the water Etta started clapping her hands with happiness and joy. Etta went swimming every month after that, until just before she passed away.

During the time of the release of the film 'The Kings Speech' an activity based around royalty and the abdication was arranged one afternoon in the care home. Several people in the group were able to recall the occasion in detail. Two residents **Lola and Edith** were particularly interested and expressed a strong desire to see the film. Both residents were living with a dementia and although cinema trips had been arranged in the past, neither had expressed an interest to attend. The activity coordinator contacted the local multiplex cinema and explained the situation. A less busy showing time was discussed and a time was agreed to attend. Lola and Edith dressed in their finest outfits and went to see the film with the activity coordinator. Lola was particularly animated and, although was unable to sit all the way through the film, both loved the film and recalled the outing over several weeks.

High tea events were often held in the care home but were very much looked forward to by many residents. From the development of individual life stories it was discovered that several residents had, over the years before moving into the care home, visited a local grand hotel that specialised in high teas. A small group of residents started to visit the hotel weekly. Many of the residents, whilst in the care home, needed support to eat and drink, but in the social group they required very little help. Over time, other hotel high tea regulars started to join the group and friends were made.

Molly was a Roman Catholic and her faith was extremely important to her. When her Priest, who arranged an escort to her church died, the Priest who took over the parish acknowledged that her attendance was important to her. He felt that due to Molly's dementia she was too unsettled to attend and he would visit her to take communion. During this time it was noted Molly was less engaged with others. Following a discussion with the Priest it was agreed the visits to the church should resume. One of the care team members who shared Molly's faith attended the church with her. From arrival, Molly became animated and engaged in her surroundings. Without prompts or support Molly received communion and could recite whole prayers. Over the coming weeks, the church community embraced Molly and started to visit her in the care home. As Molly's illness progressed and she was unable to attend the church the Nuns from the local convent, some of who were very elderly, visited her daily. This enhanced the last weeks of Molly's life.

Summary of points to support the workforce to facilitate meaningful activity:

- Consider all that has made the person unique. This means knowing the person's former lifestyle, work history, hobbies and recreational and social interests, travel and significant life events
- Focus on conversations rather than direct questions and you will start to make the connection with the person
- Know what the person can do rather than not do and discover the person's interests and preferences, strengths and talents
- Formal activities and events have their place and can be very successful. However, they should not be the only things happening
- Encourage individual participation and remember that the 'being in the moment' may be more important than the outcome
- For people in the later stages of the illness, encourage sensory experiences and explore all forms of communication
- Risk-taking should be proportionate, measured and positive
- Be imaginative and do not be afraid to go with the flow. Spontaneity and flexibility is key and if the outcome is not what you intended that's fine
- Support the person to take part in new activities and experiences
- Be sensitive to cultural differences
- Choose activities that support the person's perception of how they see their role at that moment
- Encourage an area of responsibility, no matter how small
- Exercise is important even if it is only possible for the person to change position. A reasonable amount of exercise can offer many benefits, including improved sleep patterns and increased feelings of wellbeing
- Keep activities simple. It is very important that any activity does not contribute to anxiety or feelings of ill-being or failure
- A person's abilities can fluctuate from day to day. Activities should be adapted and revisited if not successful or enjoyable straightaway
- Don't over stimulate. The quality of the time together is more important than lots of options to choose from
- Use technology, such as a tablet computer. It is portable, light and provides instant access to images and music to provide 'in the moment' resources.

Reminiscence and staff development

Five top tips for other managers:

1. Choose themes that are likely to spark positive memories and support appropriately in relation to people of different ages, gender and backgrounds
2. Reminiscence objects do not need to be old. Modern objects and replicas can also be used to stimulate memories
3. Care staff do not need to know what each object is. Let participants share their knowledge to increase their self-esteem
4. When singing, give each person words printed on song sheets even if they are not able to read. Always use black print on yellow paper to assist with visual impairments
5. Make a display of all the reminiscence objects to ensure there is always something to stimulate a conversation, and that all staff, visitors and volunteers can be involved. Objects need to be safe to handle, but don't worry if people move them around the care setting, they are there to be used.

'Memory Plus' is a training and resources package delivered by Leicestershire County Council Museums Service which enables care staff to deliver a series of facilitated activities to people with dementia. It utilises museum collections and other resources for traditional reminiscence activities, which focus on stimulating memory, alongside new therapeutic activities using various art forms including music, singing, movement, drama and sensory stimulation.

The training package is delivered alongside mentoring and supporting toolkits to enable care staff to deliver meaningful and engaging multi-sensory, therapeutic reminiscence activities with confidence. Resources are suitable for use with people of differing levels of dementia. A variety of themes enable care venues to establish a rolling programme of training and activities throughout the year.

During 2011/12, Leicestershire County Council's Museum Learning and Engagement Team researched, developed and tested a number of activities using museum collections and other resources for audiences who do not normally use museums or their collections. These included activities designed specifically for people with dementia, which were trialled in a number of care settings including residential care homes, day care and hospitals. There is substantial evidence that museum collections can provide an excellent resource for activities due to their familiarity and being easily recognisable as well as their tactile nature.

Evaluation showed that the activities had a positive impact on the wellbeing of the participants who have dementia, but also identified the need for training for care staff to ensure they have the skills and knowledge necessary to use the resources and museum collections effectively.

Memory Plus is now delivered to care settings as a training and resources package. Care settings sign up for a year-long programme which includes one full day and two half days of training plus mentoring within the care setting.

Memory Plus training is aimed at care providers with differing experiences in the delivery of activities. Staff that are new to this area of work benefit from guidance and ideas and are also given confidence to take on this role. However, it is also appropriate for experienced activity co-ordinators who would like to add a more multi-sensory approach to their work.

The training uses the knowledge and experience of museum education staff to give care staff tips on using museum objects as a trigger for memories and for multi-sensory work. Care staff work with the resources and are given activity ideas for group work and one to one sessions, alongside tips on how to get the most from the resources available. Group size is limited to ten per training day to ensure that each member of the group is able to fully participate in the training and discussions and to share ideas and best practice. Following the training, care staff are encouraged to share what they have learned in their care setting with other staff.

The accompanying toolkit reinforces skills learnt during the training and provides additional guidance on planning and evaluating sessions, adapting sessions for differing levels of dementia, guidance on undertaking multi-sensory work, key communication tips and signposts to further information.

Mentoring is also provided by museum education staff. This can either be a revision of the training, again reinforcing skills learned during training, or activities can be delivered in the care setting by museum staff, demonstrating how they deliver activities using resources provided.

Memory Plus has been developed into themes of resources and activities, with care settings loaning each theme for approximately one month. Themes have been carefully selected as those most likely to trigger positive memories and to have life experiences common to many people. To date Hollywood Glamour, Beside the Seaside, Royalty, Childhood, The Great Outdoors, Working Life and The Seasons have been developed. This use of themes gives continuity and reinforces memories of previous sessions.

Care staff are also encouraged to create a display for the duration of the loan period to encourage continued engagement with the resources and to enable them to be used to share memories with other staff, visitors and volunteers.

Activities linked to each theme have been developed to be suitable for a range of dementia types, from early onset to advanced, and cover a range of activities such as multi-sensory, movement and music. There are approximately 12 activity suggestions per themed box, including suggestions for different sized groups and one-to-one. They also offer different ways of engaging, allowing activities to be personalised to each individual participant.

Activities have also been developed for care staff to share knowledge learned during training with volunteers or visitors, who are also able to use the resources and deliver some activities.

Evaluation has been undertaken to identify the benefits to both care staff receiving training and to participants in the activities.

The most direct benefit for care staff is the increase in confidence to providing activities and engaging with residents. However, other benefits result from delivering the activities including the opportunity for care staff to get to know the people they are caring for better as individuals, strengthening understanding between them and creating empathy. Staff learnt new stories from residents with dementia, even after several years of caring, as the activities have sparked memories to share.

Care staff have also used Memory Plus to assess the levels of functioning of residents whilst delivering activities. In some cases, care staff have been surprised by the engagement of residents, whilst in other cases care staff have been able to assess that residents have progressed to more advanced dementia.

Other benefits identified for staff have been renewed motivation and inspiration, improved self-esteem through the development of new personal skills and by helping the participants feel special and valued. Feedback from care settings and those staff that have participated in the training has been positive.

For the participants with dementia, the new skills and confidence of care staff has led to new opportunities and motivation to join in, increasing levels of engagement. There have been more opportunities to communicate with staff and other residents, with residents changing their normal social groups to share their stories and memories more widely, as positive memories have been stimulated. Other benefits have been the opportunity to share their own life experiences with staff and visitors, with improved self-esteem and a sense of fun and positive atmosphere being brought to the care setting. This has led to an increased sense of wellbeing.

Museum collections offer many opportunities for reminiscence, can be a valuable resource for triggering memories and an excellent starting point for activities. Memory Plus has demonstrated that care staff can effectively use these resources for activities and that, by participating in training where ideas and best practice are shared, the benefits to both care staff and people with dementia can be hugely beneficial.

Memory Plus has contributed to care homes being able to provide an informed and effective workforce and has been supported in Leicestershire by the Adult Social Care Compliance team. It recognised the valuable contribution Memory Plus is able to make in enabling care homes to provide a wide range of activities within the home, as identified in the Quality Assessment Framework. It has also been supported by the Learning and Development team for the strong training element offered to staff.

For further information about Memory Plus, contact:

engagementteam@leics.gov.uk

Culture to support person-centred approach

Five top tips for other managers:

1. Communication and co-ordination of care is key
2. Even though a person lacks capacity to make decisions regarding care planning, the person remains an individual with specific values and wishes. As far as is possible, these need to respected
3. Planning in advance ensures that, as and when the person deteriorates, everybody knows what is happening
4. Partnership working is imperative
5. People with dementia can have an extended period of time when they are receiving end of life care

It is estimated that 25% of older people have dementia. In care homes this rises to nearer 80%, according to the Alzheimer's Society. This section considers person-centred planning for people with dementia and, whilst acknowledging the problems relating to this level of care and support in an extra care setting. It demonstrates how, with effective planning and improved knowledge, a person with dementia can receive good quality person-centred care until their death.

Extra care housing offers specially designed housing with the addition of 24-hour on-site care. Schemes or 'courts' typically contain 30–60 self-contained apartments with full kitchen and bathroom facilities designed to mobility and wheelchair access standards. Older people who live in extra care housing have the full legal rights of occupation associated with being tenants or homeowners, in combination with access to 24-hour on-site care, which is delivered flexibly according to a person's changing needs.

Housing 21 has a commitment to providing individualised responsive care and support to people over the age of 65. Most residents of extra care housing schemes see it as their home for life. For many, that means it is also where they would choose to die.

Dementia is a terminal disease in that it is progressive and there is no cure. However, the duration of the disease is protracted. The care needs for someone with dementia are often multi-faceted and complicated. People with dementia often have other illnesses alongside their cognitive problem and this, coupled with the person's lack of mental capacity to engage fully in decision-making processes at the latter stages of their disease, can make care planning and care provision difficult. The advanced stage of dementia is considered to be the last third of the person's illness; where they are often heavily dependent on others for care. This stage of the disease can be difficult for carers and families to experience as often the person has limited communication and capacity to engage with their care planning.

Whist people with a diagnosis of dementia lose many cognitive and other skills as well as their physical function, they also retain many aspects of their personality until very late into their disease progression. It is therefore important to recognise the person behind the disease and respond to their specific needs and wishes and not to assume a 'one size fits all' care pathway.

Person-centred care and the concept of personhood is the keystone to effective and good quality dementia care. However, as an individual's dementia progresses, formally involving them in the planning of care provision becomes more difficult due to the loss of mental capacity as they become unable to retain and digest complex information, and at times, communicates their decision in any way.

Capacity and decision-making is specific to time and place. Though a person with dementia may be deemed unable to make a decision regarding their place of care or their specific health treatments they may be able to be involved in decision-making at a much more local and informal level. It is important for all those working with people with dementia to work towards enabling them to be as involved in their care as much as possible.

Providing physical care is often a significant part of advanced dementia care. Often, this care involves carers providing a level of intimate support which, if not done in a way that is sensitive to individual needs, can result in the person feeling dehumanised and not respected. By recognising non-verbal cues and patterns in a person's behaviour, carers can begin to determine how a person prefers to be cared for. Carers can record these cues and patterns in a variety of ways, which will then help to plan care for the future.

An example of this is 'This is Me', produced by The Alzheimer's Society and the Royal College of Nursing. It is a two-page document for carers to record how a person with dementia likes to be cared for.

Though physical care is often a significant part of advanced dementia care, emotional, spiritual social and psychological care is also just as important in providing person-centred dementia care. It is these elements that make a person an individual. People with advanced dementia may not necessarily be able to articulate clearly their thoughts, fears and anxieties. However, by acknowledging and validating a person's feelings behind the words or behaviours, carers can help a person with dementia feel safe and secure.

One example of this is Mrs Li, a 93-year old Asian lady who lives in a nursing home. She has Alzheimer's disease and speaks no English. Her son is concerned she is not eating very much. She has significant contractures in both legs which makes positioning her difficult and therefore she spends all of her time in bed in a semi-recumbent position. Mrs Li does not like to be assisted to eat and therefore the care team give her sandwiches and she feeds herself.

A staff member had a conversation with Mrs Li's son and enquired what Mrs Li would have eaten at home. She was told that she would normally eat steamed fish and rice. The staff member then contacted an occupational therapist for a seating assessment and obtained the advice and equipment so that Mrs Li could sit out of bed for her meals. The staff member then asked the kitchen to provide Mrs Li with food that she could recognise and was familiar to her palate.

The staff member also invited an interpreter to assist her in assessing Mrs Li's mood. Mrs Li scored moderately on the geriatric depression scale, though some of the questions she was unable to answer as she was unable to process the question due to her dementia. The staff member looked at Mrs Li's room and felt it was not very stimulating. She spoke to the son and suggested ways to make Mrs Li's room more stimulating and interesting. She also spoke to the doctor, who commenced Mrs Li on a low dose of antidepressants.

After a month, Mrs Li was assisted to sit in a chair for her meals and was given culturally appropriate food. Her room had a mobile in made from crystals which caught the light and gave her something to focus on. Rather than the television playing English programmes, Mrs Li's son recorded Chinese TV and radio and staff played this to her. Mrs Li appeared much more engaged with her surroundings and started to eat much better.

People with dementia can require care for a significant period of time. Staff need to be enable to understand and recognise the changes in a person's health status that may indicate that they require an alternative approach to care. By working closely with other agencies involved in care provision the person with dementia may be able to remain in their home and receive individualised and person-centred care.

Innovative use of information technology to help staff to support people with dementia

The Partnership in Care offers high quality nursing and residential care services across Suffolk and works closely with the Registered Nursing Homes Association. The management team of The Partnership in Care is continually looking for ways to introduce information technology to support their staff teams in care homes.

Care and Nursing Homes have used information technology for many years, but most commonly this has been in the administration of care. This section documents work undertaken within the MIRROR project, which looks to utilise information technology to allow staff to reflect on their practice. This aims to improve the quality of care delivered for those living with dementia by the development and testing of prototype apps, which are subsequently tested in limited pilot situations to prove their impact.

The Registered Nursing Home Association undertook research of its members in 2009 to determine the extent of the use of Information Technology in Nursing Homes. It found that whereas all homes used the technology and had access to an internet link, the usage within the home was, in the main, limited to administration. Whilst payroll and word processing were available, the majority of staff were unable to access such systems.

Over the past five years, since that research, we have seen the widespread adoption and use of smartphones as well as many social networking systems. Care staff (like the general population) have become users of such technology in ever increasing numbers with the consequent opportunity to utilise those skills to improve the quality of care delivered to those living with dementia.

The MIRROR project seeks to research how information technology can enable reflective learning. In the case of the Registered Nursing Home Association care staff have been targeted to support those living with dementia, by enabling a series of systems to be piloted and tested to determine the potential improvements to the care delivered. These range from systems to record, store and access the life history of those being supported, the collection of more detailed information of the care required and delivered, as well as support to care staff, in the form of better information and advice to enable them to deliver effective care. This latter group of systems take the form of either advice to suggest potential courses of action or role playing in the form of a computer game or simulation of a situation to allow staff to test likely responses, allowing them to reflect on the appropriateness of the care they are delivering.

Life History

The availability of information relating to the life history of the individual being supported is frequently vital to provide appropriate care. Such a life history will always include family members, friends, education and employment history, special memories and events, as well as hobbies, favourites and statements about how the individual likes to spend their day and what activities they choose to undertake. Besides written material on these topics, it can be beneficial to have photographs and pictorial information available.

When this information is collected and maintained electronically, it is possible to have friends and relatives contribute relevant material. This allows those supporting the individual to refer to visitors and relatives by name, even showing the individual photographs to stimulate memory. Behaviours which are not immediately understood can be reflected upon by reference to the information within the life history, and in future, the data within the life history can be used to search for materials which may be of interest to the person on the internet. For example, favourite music, visual material of holiday locations or video material of hobbies can all be accessed to provide appropriate stimulation or prompt meaningful activity.

Information capture

The 2009 survey proved that the vast majority of Nursing Homes hand-write the care plans and records of care delivered. Where this process uses information technology the records are typically completed at the end of a shift. This results in a brief synopsis of the care delivered being recorded since the actions were completed several hours earlier.

The use of mobile devices (phones/tablet computers) allows the care delivered to be recorded at the time of delivery or support. It was assumed that the use of such devices would result in more quality data being captured. The early pilots of this approach proved this to be the case and hence additional piloting of different detailed approaches should refine the approach in order to optimise the situation. Hence the size of the devices, capacity to input limited or unlimited data, and whether the spoken word or typed data achieves optimal results, is to be determined during the final stages of the project.

Advise appropriate care

Care staff encounter a vast number of very different situations when supporting people living with dementia. Whilst the individual may present with similar symptoms, for example agitation, boredom, or other characteristics, which challenge care staff, the causes of such behaviour are many and varied. In an attempt to spread good practice an app has been created which prompts staff when faced with situations which they have not experienced before. Hence the app allows care staff to enter key characteristics of the behaviour and it will suggest possible courses of action or coping strategies. Staff can enter information into the app when they have identified new situations or new coping strategies. The app can access data from other sectors to enable staff to access coping strategies which may not have been considered before, but which have been found of value in other settings.

Talk Reflect – Help on difficult conversations at work

Although the list of subjects in the 'mandatory' training of care staff is long, it is unlikely to cover all the areas of demand in this complex, person-centred service. While health and social care training has concentrated on the physical sides of care, 'softer' issues around difficult conversations with the person with dementia, their relatives and other interested parties, on a host of uncomfortable subjects e.g. sudden deterioration, complaints, and even 'end of life' care, are often left to chance. And so an app was developed to help, both to record and share such experiences, and to learn from others' experiences. From initial testing it also became clear that difficult conversations were not just between carers and relatives, but could also be between carers and residents, between carers and colleagues, including a number of outside agencies. Accordingly the app was extended to include these scenarios.

In addition to recording the nature of the conversation, the Talk Reflect app also allows you to quickly capture your mood and thoughts about the conversation, and those of the conversation partner. These documented conversations are the subject of discussion, reflecting on these incidents, either individually or with your colleagues, and exchanging experiences. Agreed best practice – 'outcomes' - according to local conditions and personal considerations, are then easily documented and shared. This app is best used by a group of staff, to note and share difficult conversations, and outcomes, using a tablet computer. The information is used by the group, or an individual, to reflect and find solutions for similar opportunities in the future.

Reflecting and learning through gaming - Think Better Care – A 'serious game'

'Serious game' is a pretty good description. It looks and feels like a computer game, but the content is serious. This app has built a virtual care home, where the player can move around, meet people, and do things. She, or he, can talk to others and perform tasks as in the real world. They will also come across challenging situations, as in reality, and be offered choices on what to do. These decisions have consequences, both positive and negative.

Within the game there is guidance from a virtual tutor, who provides feedback on choices made. The game provides an automatic history documentation for later reflection. As a new worker, you are given a mobile device, which gives you access to your task list and a variety of resources, including access to the Life Stories of residents. Based on person-centred care principles, motivation within the game is provided by trying to maximise resident satisfaction and improve time management.

Serious game gives us a chance to play out real scenes, real problems, and explore options, but in a safe, virtual environment. The philosophy of the game is 'practice in a game, in the virtual world, and be better prepared for the real thing'.

Staff acceptance of information technology

Managers frequently cite staff reluctance as a reason to limit the use of information technology within care. Staff are worried that they would somehow 'break' the computer is often heard. Other managers might comment that they want the staff providing care and not sat at a computer in the nurses' station. Yet the last decade has seen a massive increase in the amount of record keeping which we are all required to maintain. Further, the number and complexity of risk assessments and the continued relevance and updating of those assessments is an issue that is not going to diminish in the future.

In practice, whilst staff can be a little reluctant in the first few days of adopting any new system, within a couple of weeks any reluctance has been overcome. It is common for all staff to use the system. Sometimes, issues are identified such as dyslexia or poor vocabulary or spelling and can be either addressed by software such as spell checkers or through additional support to the small number of staff affected.

There is considerable potential for improving the quality of care to those living with dementia by utilising information technology. This can either be observed directly by access to better information of the individual being supported, by providing better information to care staff, or by reflective learning by care staff.

Reflective Learning and Supervision

Five top tips for other managers:

1. Recognise the emotional and psychological impact of the work and put strong support structures in place
2. Learning and practice are intrinsically linked, so handovers, team meetings and supervision should always be seen as opportunities to develop
3. Develop senior staff to become reflective leaders
4. Encourage creativity and collaborate with organisations that can inspire staff to find new and meaningful approaches
5. Lead by example.

This chapter looks at how Jewish Care provides reflective learning and supervision for staff working with people in the advanced stages of dementia. It is important for the development of the workforce, because it shares Jewish Care's experience and insight into what they have found effective for developing, sustaining and supporting confident and compassionate care teams.

Jewish Care's managers ensure that staff members have regular one-to-one supervision sessions with senior staff, where they can explore how to build meaningful relationships with clients. Supervision is seen as a place to develop, learn and grow. In addition, staff are encouraged to use team meetings, handovers, and peer support to continue reflective learning on a daily basis. From staff members' initial induction onwards, training in person-centred approaches helps them to develop into reflective practitioners.

The key points are:

- Reflective learning is an ongoing process that is enriched by formal and informal training and supervision.
- It is important to provide opportunities for staff to engage with creative projects that can build their confidence in reflection, and can enhance their ability to engage with people in the advanced stages of dementia.

Examples of good practice are given over the page. The evidence to support these examples is outlined through the outcomes achieved with people living with advanced dementia.

1. Ongoing training programmes

Jewish Care is committed to raising the level of dementia knowledge and skills to promote quality care. All care staff members have an initial induction of five days that includes a day on person-centred care and dementia, and an introduction to the skills for reflective practice and learning. The organisation gives all team leaders and nurses the opportunity to gain the Qualifications and Credit Framework (QCF) Dementia Certificate. The knowledge specification is taught by two members of the Jewish Care's dedicated Disability and Dementia Service, who provide the main dementia training programme. Staff members taking this qualification are encouraged to share their experiences and are supported to develop skills to reflect critically on their work with clients. They produce reflective accounts, as part of the assignments.

An example of this is Gladys who wrote about her experience of working with a resident and her family to promote a good death. Sadie's favourite music was played, she was given gentle massage each day and her family was encouraged to visit day and night. When Sadie died Gladys went to the funeral and the family wrote a letter of thanks to the home praising Gladys. When writing the reflective account Gladys felt proud that she had been part of the process and was able to share what she had learnt with her team.

2. Dementia Champions

Every two months a group of staff dedicated to promoting good practice in dementia care (champions) meet together for a day to share their experiences and to discuss tools for delivering quality person-centred care. They use the V.I.P.S framework as a basis and structure to order their reflective practice (http://Intsoftware.com/vips-dementia-toolkit). In each session every champion is given opportunities to explore care practice in their place of work.

Susan spoke about working with a resident (Hettie) who had been looking for a poem to be read at her funeral. Susan felt comfortable talking to Hettie about her End of Life wishes. She shared that this was because she had spent the last two champions' sessions looking at loss, end of life and the importance of listening and recording people's wishes. Susan said she would have been afraid of having this type of conversation, if she had not had the opportunity to explore end of life issues in champions' meetings.

3. Music for Life

Every year Jewish Care gives 15 care staff the opportunity to take part in Music for Life projects. Music for Life is run by the Wigmore Hall and Dementia UK. During these projects, staff members are supported by a dementia development worker to reflect on their participation and learning in the project. The Music for Life projects are led by classical musicians. During the projects people with advanced dementia join with the musicians and staff to create improvised music together.

An example is when Mr.Y took part in a Music for Life project in the residential home where he lived. He struggled to participate due to his impaired vision and lack of motivation. He had an incredibly sad side to him, not surprising for a Holocaust survivor who had been in one of the death camps. The musicians did manage to build a relationship with him.

By the end of the sessions he was participating in holding instruments, and he seemed genuinely happy to take part. One of the main stabilising factors was having a member of staff sitting next to him throughout the project. He had a very close relationship with her. She understood him and was able to encourage him to take part. She reflected on the experience and, together with the dementia development worker, she devised an action plan for Mr Y:

- To hear Jazz music, especially Louis Armstrong
- To not always take the 'NO' that he usually comes out with at face value. With the right kind of encouragement he can participate
- He is an intellectual and likes to be treated this way
- Discussion on a one-to-one works well for Mr.Y. Groups would be hard for him
- His eyesight limits him, so help him visualise colours through description.

4. The Eden Alternative Project

When The Eden Alternative came to the attention of Jewish Care, they commissioned training for managers and social care co-ordinators. The philosophy behind the Eden alternative is the belief that people living in care homes, including people with advanced dementia, face issues of loneliness, boredom and a sense of helplessness. To overcome these emotions it is important that they experience contact with children, nature and animals as well as meaningful relationships with those around them. Staff are asked to engage in a reflective process and to view dementia as a 'life experience' that needs to be viewed through the eyes of the person to help better understand their needs. They are encouraged to look at the life history, values, relationships and coping strategies to find resonance for the person with dementia and provide more meaningful activity. An example of this is Jewish Care's Ella and Ridley Jacobs Home that has recently achieved the certificate acknowledging that the staff, volunteers and residents are well established on the Eden Alternative journey and 'have fulfilled all the requirements to be included on the UK register'. The home is very creative in finding meaningful ways to bring nature close to residents. Recently, they hired an incubator to nurture the hatching of eggs. Residents had the opportunity to enjoy the newly hatched chicks, and for many, it brought back memories of childhood. In this home, residents experience that they are at the centre of life and activity.

How to improve things further still

The above are a few examples of how Jewish Care had found opportunities to develop reflective learning with staff. Jewish Care is committed to improving things further by a continued commitment to ensuring that QCF and other courses are delivered in ways that stimulate reflective learning. Collaborations with other organisations are being forged to ensure that staff have allies to promote creative and reflective working approaches with people with dementia.

Jewish Care is committed to supporting staff to engage in reflective learning. The examples above enhance the traditional structures of supervision and team meetings, with a variety of creative ways of offering staff opportunities to develop their reflective skills. They recognise and actively collaborate with arts and other social enterprise companies to ensure staff have opportunities to grow and develop through participation in their projects.

Promoting Dignity in the Advanced Stages of Dementia

Five top tips for other managers:

1. Dignity in life is paramount, but do not forget dignity in death
2. Dignifying care is achieved through showing someone respect, openness and warmth
3. Dignity can mean something different to every single person, and can change over time
4. In advanced stages of dementia, it is important to consider the environment, value of personal possessions and the value of knowing a person well to ensure dignity
5. For people with the advanced stages of dementia, it can be the little things that count.

Hartford Care offers residential, nursing and day care services for older people and those who experience dementia, including advanced stages of dementia. Its aim is to create a warm, safe and happy environment in which residents feel they are a valued member of society, whilst always being committed to providing the highest possible standards of care. Hartford Care believes that each and every person they support has an absolute right to choose the way they live their lives and will do all they can to support their chosen way of life. It actively involves its residents in their care to promote and enable as much independence as possible. Each and every day, the utmost regard is given to maintaining residents' dignity and independence through ensuring that everyone is treated with respect to promote dignifying care. This is achieved through a commitment and focus on workforce learning and development. Hartford Care's Code of Conduct has an emphasis on dignity. Each and every member of staff at Hartford Care:

- Treat each person as an individual
- Strive to establish and maintain the trust and confidence of residents and carers
- Promote the independence of residents whilst protecting them as far as possible from harm or danger
- Respect the rights of residents, whilst seeking to ensure that their behaviour does not harm themselves or other people
- Uphold public trust and confidence in social care services
- Be accountable for the quality of work and take responsibility for maintaining and improving knowledge and skills.

Supporting dementia workers

Hartford Care places dignity at the heart of all of its care and support, promoting dignifying care in all areas of the company. People working for Hartford Care recognise that dignity is unique to each and every person and is reflected through treating people, from residents to visitors to staff members, with respect, honesty and warmth at all times.

In advanced stages of dementia, offering dignifying care can be more complex, especially when an individual is not able to communicate what dignity means to them. It is therefore important to ensure that all staff within Hartford Care have an in-depth knowledge and understanding of the individual in order to be able to support them and respond appropriately and sensitively to the person, to ensure dignifying care and support is given.

Hartford Care focuses on the individual experiencing the advanced stages of dementia in order to offer care and support that is dignifying. For these individuals, there are several key factors that all staff within Hartford Care promote and strive to maintain in order to ensure the person's dignity is upheld. This includes ensuring each person is treated as an individual, that services and care are shaped around them, that the environment is one that promotes independence and reminiscence and enables an individual to feel safe, that the culture of the workplace is one of learning and honesty and that any practices that may not be seen as promoting dignifying care are challenged and addressed.

Some of the ways in which Hartford Care promotes dignity, when someone is experiencing the advanced stages of dementia include:

- All care and support staff wear brightly coloured polo shirts within the care homes. This is because eyesight can diminish with age and can be helpful to someone with sight loss to recognise and be reassured by those staff that can support them. For an individual who may not be able to remember staff names or faces due to short-term memory loss, the brightly coloured shirts help to the staff that can offer support.

- Within each of the homes, all toilet doors are painted golden yellow to promote independence and assist those people with or without dementia to find a toilet

- Staff members sit with people with dementia and talk about their lives, where they are from, what matters to them and who is important to them. The home then makes a shortlist and displays it, with the person with dementia and their relatives' permission, in their room. For a resident in end stages of dementia this enables staff to talk to them about things the person has done, things that interest them so even if a resident may not communicate, they may hear things that can help them feel reassured and may trigger connections

- Dignity trees are used for residents to write down or draw pictures that illustrate what dignity means to them as an individual, and what's important to them. They are used to remind those supporting and caring for people in the advanced stages of dementia that each person is a unique individual

- When an individual first comes to live in a Hartford Care home, a full assessment is undertaken which includes gaining background information about their life and important life stories, as well as end of life care wishes. This enables a history to be built up and enables staff to get to know them as a person. Family carers also help staff and build relationships between all of those involved in the care and support of the individual.

- Each individual has an individual medication cabinet that is secured in their room in a discreet place on the wall in their bathroom. This ensures greater privacy and respect for an individual who requires medication to be administered.

- Dignity in death is just as important as in life. All staff are supported and trained to ensure that dignity is upheld even in death, ensuring the individual is washed gently with warm soapy water ensuring that this is carried out in a respectful way, is wearing their favourite clothes, which are ironed and well presented, that make-up has been applied if the individual wears it, and a flower placed on the person before the undertakers arrive.

Ensuring that people who are experiencing the advanced stages of dementia are treated with respect, warmth and honesty is paramount and ensuring that dignifying care and support is provided to uphold the dignity of each individual. Dignity is at the heart of all care and support, and this is true in all aspects of care and support at Hartford Care. Staff members hold dignity as a core value and ensure that it is promoted at all times. Learning and development programmes focus on the dignity of the individual and ways in which staff can ensure they are offering dignifying care at all times, in life as well as in death. The little things count to ensure that a person feels that their dignity is being upheld.

End of Life Care (EoLC) for people in the advanced stages of dementia

Five top tips for other managers:

1. Find out people's wishes as soon as possible, as cognition may decline
2. Have a plan and communicate it to everyone clearly
3. Get support from your GP, district nurses and specialists, where possible, for best interest decisions
4. Use every opportunity to learn and improve your service through reflective practice
5. Strive to maintain a stable staff team, including the manager, to provide a consistent approach

Northhill Care Home is a family-run private care home based in Sheffield. It has been part of the local community for the last 18 years and has seen many changes during this time. The manager and a 'champion' have recently been involved in the Skills for Care EoLC Programme across Yorkshire and the Humber, commissioned by the Strategic Health Authority.

By far the greatest change has been the increased number of people coming into care with more severe dementia. Sheffield has an aim to care for people in their own homes for longer periods of time, which means that when people do enter into care homes, their needs can be greater and they are less able to communicate their wishes. This impacts on all areas of care but has particular challenges with respect to planning and delivering end of life care.

Northhill aims to provide end of life care for those service users who wish to spend their final days in their home with familiar people caring for them. This is even more important for people with advanced dementia who may find the change in environment and carers very upsetting. These challenges have led to Northhill looking at their end of life care with a focus on dementia, and asking how they can ensure people with advanced dementia have their needs and wishes recognised.

Northhill found that when producing the top tips that many of them are interlinked and dependent on each other for success, but they were a helpful structure or checklist.

In all good end of life care, communication is the key. Northhill chose to create a post for an end of life care champion to work alongside the manager in delivering high standards in end of life care at the home. Here the end of life care champion has a dual role and is also the dementia champion, which is ideal as many parts of the role overlap.

They already use a document specific to Northhill to ask service users about their end of life wishes. It was developed with a researcher who undertook a piece of work with Sheffield Teaching Hospitals. Many homes use the preferred place of care document but Northhill found it did not suit their setting. It was difficult for people with dementia to use as the questions are not specific and are open to interpretation.

The Skills for Care 'Common Core Principles for supporting people with Dementia ' indicate that questions put to people with dementia may need to be framed so the person can give a yes or no answer and short sentences may be helpful. Northhill's document focuses on conversations and planning around end of life care, with short questions and prompts for the person using the service and their family carers.

The end of life care document, an Advanced Care Plan, asks people their views on CPR (Cardiopulmonary Resuscitation), their preferred place of care at time of death, who they want to be involved in their care and also their wishes after death i.e. cremation, burial, hymns, readings and the people who they would like to be invited to the day. This can sometimes be challenging to complete with someone with dementia. Northhill do ask family carers and friends for their opinion on what they think the person would want, bearing in mind that people may also have their own views that could influence their decision-making.

Northhill uses this document as soon as possible, since service users with dementia's cognition can decline at any point. They revisit the document regularly, with people (provided this doesn't distress them) and check that their opinions have not changed. Sometimes people feel they are unable or unwilling to address end of life care just yet, as they feel well and may lack insight into their condition.

Occasionally, family members do not feel able to speak on behalf of the person for many reasons. In these situations it can be difficult to obtain the information and can feel very frustrating for the staff. They need to recognise that people come to decisions about end of life at different times.

The end of life/dementia champion has had to be creative and think about other documents and methods of obtaining information. Northhill currently uses a life story document that gives some historical information about people's lives, which is very helpful for dementia care. They are also developing the use of the Alzheimer's society document, 'This is Me', to support carers to understand what is important to people with dementia.

They have often found that if you know how someone has lived you can plan for their care and support at the end of life better.

Using active listening and being open to people trying to start 'the conversation' is something that is encouraged at Northhill. People with dementia may struggle with a formal discussion but may start informal conversations when they feel most secure or relaxed. Giving staff members the skills to recognise this and respond appropriately, and then to document this conversation, is really helpful.

Having a plan is the next step on from asking for people's views. At Northhill they have found that to have a clear plan for what people want at the end of life is very empowering for the staff team.

Any plan needs to be clear and answer all scenarios like 'what do you do if' and who to call when etc. It needs to be agreed with the service user where possible, the GP and family members.

Having a plan helped staff at Northhill advocate for a person using their services, and prevented an admission to hospital. It facilitated a good death at the home in familiar surroundings with her family and the carers she recognised with her. It helped the staff be assertive with the out-of-hours team who wanted to admit the lady to hospital, and for the lady's wishes to be respected. Having a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) form in place and ensuring that they knew the person's preferred place of death enabled the service to provide evidence for their practice.

Steps 2 and 3 in 'Achieving success in end of life care' talk about assessment care planning and coordination of care. Having a clear plan helps the home to achieve this.

The plan needs to contain guidance for the staff team about how to respond to the service user who may ask questions about their illness or may not have insight into their condition. Northhill have found that in this situation it is important to be led by the individual. An example of this is when a gentleman with terminal cancer was admitted. He had been counselled about his condition but seemed to have no insight into his illness. He was able to inform people of his symptoms of pain and nausea and ask for support, but he did not talk about his cancer. After discussion with the GP, the plan of care was to support his symptom management but not inform him each time about the cause of pain. The home uses a pain chart to document and measure pain which was developed using a number of tools, in particular the PACSLAC (Pain Assessment Checklist for Seniors with Limited Ability to Communicate). This includes cues for assessing pain in people who may not be able to verbally express their pain and asks carers to consider facial expressions, movement, mood and physiological changes. Staff at the home used this tool to identify pain for the gentleman and provided appropriate care with as little distress as possible. However, if he asked the staff, they sensitively talked to him about his illness and answered any questions honestly. Planning for the worst with district nurses, palliative care teams, his GP and family helped the home to provide dignity for the man and minimised his distress, whilst having clear guidelines on what to do if he deteriorated physically.

In Sheffield, the care homes are fortunate to have access to a Local Enhanced Service (LES) from their GP practices. GPs in Sheffield have been leading on the delivery of proactive, coordinated healthcare to care home residents through a Locally Enhanced Service (LES) first set up by NHS Sheffield in 2008. The initiative focuses on developing clear lines of communication between care homes and GPs and establishing effective access to community health services, including district nursing, specialist nursing and allied health professionals. This means that the GP practice works closely with the care homes, providing weekly visits and annual reviews. The LES enables the care home to plan for end of life and review their plans. It builds relationships with the home and the GP and gives family members access to the GPs to discuss their views. Having weekly visits is beneficial when discussing end of life care wishes with people with dementia as they may need more than one visit to discuss this and may need to do so on more than one occasion.

At Northhill the team hold regular meetings and always reflect on their delivery of end of life care. Using the 'significant event' tool from the Gold Standards Framework, it is possible to identify what went well and what could be improved upon in the future. This also enables staff members to express their feelings about a person's death and this is very helpful in supporting staff to maintain good practice.

One of the most challenging issues as a manager is how to maintain a stable staff team that can provide a consistent approach. This is reliant on so many factors, but Northill have found that when staff members feel supported they are more likely to be effective and the team is more likely to be stable, which means that EoLC along with dementia care and all other areas of care are of a higher quality. Working with people in the advanced stages of dementia and at the end of their lives can be the most emotional and distressing part of a carer's role. It's important to support them with good leadership, a clear plan that is agreed with a multidisciplinary team, enabling time to reflect on the success of the care given with opportunities to share how improvements in care can be made, as well as being able to express their feelings.

In addition to the Northhill experiences above, Housing 21 has also provided a case supporting person-centred planning in respect to end of life care.

Case study

In 2007 Mrs Ellis moved from her terraced house in an inner city area into an extra care facility near her home, when she began to find her home difficult to manage. Mrs Ellis has macular degeneration and is registered blind. This, coupled with a diagnosis of Alzheimer's disease five years ago, meant she was experiencing problems preparing food and washing and dressing independently.

In 2012 Mrs Ellis fell and was admitted to hospital. She was found to be dehydrated and had some bruising. The care team at the extra care facility did not feel they were able to manage the fragile state that Mrs Ellis was in and contacted a social worker with a view to suggesting Mrs Ellis move to a nursing home. The care team also contacted the dementia voice nurse for advice.

The dementia voice nurse spoke to the care team and realised that they did not understand how dementia progressed and how to recognise when someone was in the advanced stages of the disease. The GP had not been involved in discussing end of life care with Mrs Ellis and her family. The care team lacked confidence in providing care and were concerned that they had been neglectful because Mrs Ellis was dehydrated on admission to hospital. The dementia voice nurse met with the family and the carers and established their main concerns about Mrs Ellis' care needs.

These were:

- Falls
- Eating and drinking
- Practically providing end of life care

As a result of the meeting, the dementia voice nurse:

- Contacted the GP and requested that a discussion around end of life care and resuscitation took place, along with a review of medication
- Provided specific training to the care team around end of life care and dementia, specifically with regards to eating and drinking
- Liaised with social services to arrange a falls detector to be put in place and an increase in the number of carer visits she received each day
- Arranged for a hospital bed to be delivered
- Assisted the family to complete a 'Preferred Priorities for Care' document that took into account Mrs Ellis's previous values and wishes with regards to planning her care and place of death.

The care team then felt able to continue looking after Mrs Ellis with the support of the dementia voice nurse and she remained in the extra care facility cared for by people she knew, in an environment that was familiar to her.

Qualification Progression Routes to support the workforce

Progression routes for dementia

The principal qualifications of competence for those working in social care are the level 2 and level 3 Health and Social Care (HSC) diplomas. The diplomas are made up of nine mandatory units and a bank of optional units from which learners can choose to relate to their job role or interests. Within the diplomas it is possible to take a specialist dementia pathway, which will allow learners to further tailor their learning where they are asked to demonstrate both knowledge and competence of working with individuals with dementia. There are also four specific dementia QCF qualifications available for learners:

- Level 2 Award in Awareness of Dementia

A knowledge-only qualification consisting of four level 2 units on awareness, person-centred support, communication and equality and diversity.

- Level 2 Certificate in Dementia Care

A competence qualification requiring learners to build on the learning from the award to demonstrate their skills in working with individuals with dementia (though learners do not necessarily have to take the level 2 award before embarking upon the certificate).

- Level 3 Award in Awareness of Dementia

A higher level knowledge-only qualification covering the experience of dementia, administration of medication, communication and the importance of equality and inclusion.

- Level 3 Certificate in Dementia Care

A higher level competence qualification for learners who have a more advanced specialist role in working with individuals with dementia. The certificates provide the opportunity for contextualised continuing professional development (CPD) for workers with experience in social care to develop knowledge and skills around supporting individuals with dementia so that they can provide high quality person-centred support. It is not intended that the certificates confirm competence in the social care role as this can only be truly achieved through the Health and Social Care diplomas.

End of Life Care

Skills for Care has also produced a suite of qualifications around End of Life Care. These qualifications are not dementia specific but can be contextualised to dementia care. There is a specific dementia unit in the Level 3 Certificate in working in End of Life Care which is called End of Life and Dementia Care.

- Level 2 Award in Awareness of End of Life Care

A single unit award designed to provide a basic understanding of end of life care for those who work in the health and social care sector.

- Level 3 Award Awareness of End of Life Care

Made up of three mandatory units to support the learner to develop understanding of how to provide support to individuals and their families in end of life care, and in particular during the last days of life.

- Level 3 Certificate in working in End of Life Care

To support the learner to further develop their understanding of end of life care, especially around advance care planning, to develop specific communication skills and to demonstrate competence in managing symptoms and pain in end of life care, supporting individuals with loss and grief before death and in their spirituality.

- Level 5 Certificate in Leading and Managing Services to Support End of Life and Significant Life Events

A qualification to support managers to demonstrate how they can lead and manage end of life care services that promote positive experiences for individuals and their families at the end of life.

The Level 5 Diploma in Leadership for Health and Social Care and Children and Young People also has a specific dementia care unit Lead and manage practice in dementia care.

Apprenticeships

An Apprenticeship is a combination of on and off the job training and learning. Apprenticeships are not just for young people but for all ages. They are an excellent way of supporting new people into the sector who will be working with people with dementia.

As employees, apprentices work alongside experienced staff to gain job-specific skills.

Skills for Care has designed the framework for those working in social care and the Skills Funding Agency supports the training with funding when certain criteria is met.

Apprenticeships have the scope for any specialist employer requirements to be met, including supporting people with dementia.

The programme enables apprentices to gain relevant care skills that can include anything from supporting people to get dressed, to transporting them to and from a care setting. Apprentices might work directly with people who use services, as a care worker or team leader. Alternatively, they may work in a non-direct social care role in catering or administration.

At the end of the Apprenticeship, the employee will have gained both experience and related and recognised qualifications, including a Diploma in Health and Social Care (where the specific dementia pathway highlighted above can be taken).

Working with other health and social care professionals

A number of health and social care professionals work together to support people with dementia and their carers. In addition to this, these professionals will work alongside the social care workforce to support people with dementia. It is important that the social care workforce know what professionals are there to support them, especially when caring and supporting people in the advanced stages of dementia.

Doctors support people with dementia by providing a diagnosis for the disease and also by appropriately prescribing drugs to slow the progression of dementia or to attempt to reduce some of the symptoms. The GP of the person with dementia plays an important role, and will make the initial referral to a consultant/memory clinic if dementia is suspected. Throughout the stages of the disease, the GP can support social care professionals to care for people with dementia and provide information on helpful services or make referrals to other professionals, for example if the person is very ill or is approaching the end of their life.

There are several different types of consultants who support people with dementia. These include:

- **Neurologists** – specialists in disorders of the brain and nervous system
- **Geriatricians** – specialists in the physical illnesses and disabilities of old age and the care of older people
- **Psychiatrists** – diagnose and treat a wide range of mental health problems
- **Old age psychiatrists** – psychiatrists who have had further training in the mental health problems of older people.

The consultant may prescribe drugs that may reduce some of the symptoms for a certain period, or temporarily slow down the progression of dementia. However it is important to note there is currently no cure for dementia.

Nurses

Nurses work with people with dementia, and those who care for them, in a variety of roles.

Community mental health nurses, also known as community psychiatric nurses (CPNs), are mental health nurses who work in the community; for example, in people's homes or GP surgeries. They provide treatment, care and support for people with mental health problems and dementia. They carry out assessments of people at home and can advise people with dementia and their carers on ways of coping, and of improving their health and quality of life. They do not normally carry out physical nursing tasks. The person may need a referral from the GP or consultant to access community mental health nurses.

District or community nurses have had extra training and provide advice and care for people at home and carry out various tests and assessments. You can contact a district nurse through the GP.

Practice nurses work with GPs and other community nurses and carry out a range of nursing activities within the GP practice, such as flu jabs and check-ups. You can contact the practice nurse at the GP surgery.

Admiral nurses are specialist mental health nurses specialising in dementia who work with family carers and people with dementia, in the community and other settings. Working collaboratively with other professionals, admiral nurses seek to improve the quality of life for people with dementia and their carers. They use a range of interventions that help people live positively with the condition and develop skills to improve communication and maintain relationships. Established as a result of the experiences of family carers, the charity Dementia UK works in partnership with NHS providers and commissioners, social care authorities and voluntary sector organisations to promote and develop new admiral nursing services. The charity is responsible for upholding standards, sustaining services and supporting admiral nurses in practice. You can find out if there is an admiral nurse in your area through the Dementia UK website.

Other professionals

In the advanced stages of dementia, many people will need some support to stay mobile or active, or to help them get 'back on their feet' after an operation or fall. Carers of people with dementia may also benefit from the services of these professionals.

Physiotherapists can advise on exercise for people at all stages of dementia, as well as advise carers on safe ways of helping someone to move. Home visits can be arranged.

Chiropodists can be accessed through GPs, but there may be strict restrictions on who is eligible. They assist in the care of people's feet and can aid with walking issues.

Problems with hearing, teeth, speech or sight can negatively impact the wellbeing of someone with dementia and may increase their levels of confusion or distress. The person may be unable to tell others that they are in discomfort, so it is important to make sure these areas are checked regularly. Professionals within these areas include dentists, audiologists (hearing) and optometrists (sight).

Speech and language therapists can advise someone with dementia and their carer on ways of communicating more effectively, and on relieving any swallowing difficulties.

Continence advisers can advise on problems associated with continence. They can also give information on useful equipment ranging from commodes to incontinence pads.

Dieticians can provide advice and guidance about food, nutrition and issues such as a poor appetite, weight loss, weight gain, vitamins and food supplements.

Occupational therapists (OTs) can offer advice on adaptations and equipment, and on ways of maintaining independence for as long as possible. Some OTs work for the health service and some for social services. If you think an OT might be helpful, ask the GP, consultant or social services.

Social workers have specific training and qualifications. They may be involved in assessing a person's needs for services, and in planning, coordinating and advising on services. They can also offer support and advice. Social workers may also be referred to as 'care managers' and can be based in a variety of locations including social services departments and hospitals. To talk to a social worker, contact your local authority.

Useful resources

Progress for providers	http://progressforproviders.org
Making it real	www.thinklocalactpersonal.org.uk/MIR
SCIE Website	http://www.scie.org.uk
NAPA	www.napa-activities.co.uk
The Alzheimer's Society	www.alzheimers.org.uk
Dementia UK	www.dementiauk.org.uk
VIPS Dementia Toolkit	http://Intsoftware.com/vips-dementia-toolkit
Skills for Care	www.skillsforcare.org.uk

Skills for Care
West Gate
6 Grace Street
Leeds
LS1 2RP

telephone 0113 245 1716
fax 0113 243 6417
email info@skillsforcare.org.uk
web www.skillsforcare.org.uk

© Skills for Care 2013

SfC ref: DS040