

# Supporting people with dementia and other conditions

A case study-based guide to support the social care workforce working with people with dementia who have other conditions.



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# Preface

I am very pleased to introduce the latest of Skills for Care's products which focuses on developing the skills of the social care workforce who support people living with dementia who also live with other conditions. This product has been commissioned by the Department of Health.

It is specifically aimed at leaders and managers working in services for people with dementia, and will help colleagues to develop their teams who are supporting people living with dementia when they also live with other conditions such as a disability or a sensory impairment.



The resource is a case study-based guide and has been compiled by Skills for Care working closely with social care employers across England. Developed for our sector, by our sector, we are confident that the information, advice and guidance contained within this guide will support the development of your team.

Using qualifications to develop your workforce and supporting staff working with people with learning disabilities who also live with dementia are just two examples from this informative guide which covers a wide range of relevant areas.

We hope that by using this information it will support your organisation to further develop your workforce to more effectively support people living with dementia who also live with other conditions.

We welcome your feedback and comments on this guide so please feel free to get in touch with Skills for Care staff or contact us via email at [info@skillsforcare.org.uk](mailto:info@skillsforcare.org.uk).

A handwritten signature in black ink, appearing to read 'Sarah Allen'. The signature is fluid and cursive.

Chief Executive Officer  
Skills for Care

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## Sensory impairment and dementia Vista Blind

Established in 1858, Vista is a local charity working with almost 6,000 children and adults with sight loss, living in Leicester, Leicestershire and Rutland. The organisation:

- promotes eye health to prevent sight loss
- reduces the impact of sight loss
- provides support and care for people with sight loss

Vista offers a wide range of community services for people of any age. They operate four specialist residential care homes in the local area, including two for older people with sight loss and dementia, and two for adults with learning difficulties and sight loss.

### Five top tips

1. Optimise a person's visual ability
2. Create a sight loss and dementia-friendly environment
3. Equip staff with knowledge and skills in dementia and sight loss
4. Reduce loneliness and isolation
5. Develop comprehensive support plans

The combination of sight loss and dementia can be an overwhelming experience for an individual, their family and carers. The overall disorientation a person experiences leads to loss of independence, feelings of isolation and having to face multiple losses which challenge both the person and the care service.

Difficulties in the detection and diagnosis of sight loss can be further compounded by dementia as one condition may mask or be mistaken for another. Some types of sight loss can cause visual hallucinations which can be mistaken for dementia symptoms. That is why it is so important to understand a person's sight loss.

### *In practice*

Wycliffe Home offers care for up to 48 older people who all have a visual impairment. The home is also registered to provide care for people who have a dual impairment i.e. people who have a sensory impairment and dementia.

The home currently employs 72 staff members. All of the staff have received specialist training to help them meet the unique needs of older people with sight loss and dementia.

The ethos of the home is to provide person-centred care in an environment where people want to live, family and friends want to visit and staff want to work. Each person and their condition is unique, with differing degrees of sight loss and dementia; as well as changing needs, expectations and abilities. The home therefore places a high emphasis on both understanding the needs of the person and ensuring they have the right staff.

The home supports individuals in a number of ways:

- **Optimising visual ability by understanding a person's sight loss, their diagnosis and how it affects their life.**

Staff have a basic knowledge of numerous eye conditions to help them understand the impact sight loss has on an individual. The organisation identified that someone with sight loss and dementia was not able to find their bedroom door because they could not see the standard door colour. They overcame this by having a contrasting colour around the door, choosing a colour that the person was able to recognise. They also personalised the door with photographs and pictures to meet the person's needs.

Another common occurrence is that individuals with sight loss may choose clothing that does not match. This can be distressing for someone who takes pride in their appearance. This was solved by supporting the individual to use a talking colour detector (assistive technology); which has enabled the person to group their clothes, putting the same or similar colours together.

- **Creating a sight loss and dementia-friendly environment.**

There are many ways in which the home improves and encourages independence and quality of life. Correct lighting makes a huge difference to a person with sight loss; natural light is maximised and additional lighting is used in communal areas and bedrooms where appropriate. It is important to avoid glossy finishes to floors and surfaces as these can cause confusing reflections and glare. The organisation avoids busy patterns on carpets, floors and walls as these can create visual confusion; it is much better to have clearly defined strong colour contrasts. This does not mean that the home looks plain or institutional; plants are used for sensory stimulation and enjoyment while pictures, soft furnishings and fittings all enhance the home's environment.

- **Reducing the risk of falls by keeping areas free from clutter and obstacles, as people with sight loss are at a higher risk of falls.**

Around the home corridors are painted in different colours to help people orientate themselves. This supports individuals to maintain their independence in the home as they are able to recognise the different areas by the colours they are painted or the pictures that are used. Talking signs and noticeboards are also used as these offer another form of independence.

### ■ Ensuring staff have the knowledge and skills to be able to support people appropriately.

More than 12% of people over 75 years of age have some sight loss and in the over 80s vision is reduced by 35%. In care homes, studies indicate a higher proportion of people with both sight loss and dementia. The organisation recognises the importance of adapting its core training to include supporting individuals with multiple conditions, in addition to their sight loss. It is recommended that in residential settings, in addition to having training in dementia, staff should also receive training in sensory loss and be able to transfer their learning into practice.

### ■ Creating a programme of meaningful activities that reflects individual's interests and choices.

To enable an individual's independence, staff identified that it was important to offer activities that stimulated brain activity and used their residual vision. A range of talking books, newspapers, film and audio TV description, tactile and large print books and games are offered. They also encourage an individual's choice and control and there are no activities that are off limit. Last summer residents from the home went sailing; an activity that was supported by volunteers from another local charity in a specially-equipped boat.

### ■ Developing a comprehensive support plan with the person and others who are important to them.

Vista finds that while a person with dementia may not always be able to inform us how their sight loss affects them, when staff get to know them well and observe them, this can inform their support needs. Offering choices and encouraging the individuals to take part in identifying what's important to them ensures that their life in the home is happy and that they lead as fulfilling a life as possible.

Wycliffe Home offers an environment that looks at the whole needs of the individuals that live there. The importance of ensuring the individual's condition is understood, not only from the beginning but also in how it might progress. The identification of what training is required to support all of the unique differences sight loss and additional conditions such as dementia present, is an on-going process. The creation of a sight loss and dementia-friendly environment, that changes to meet the needs of individuals living at the home, maximises their comfort and experience of life in a residential setting.

The home recognises that individuals can still become isolated and lonely but this can be counteracted by offering a range of stimulating activities that individuals can choose to be involved in. The home's commitment to developing comprehensive person-centred support plans helps to ensure individuals benefit from a fulfilling life which offers choice, control and independence.

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## Useful resources

Local sight loss charities: [www.visionary.org.uk](http://www.visionary.org.uk)

Royal National Institute for the Blind: [www.rnib.org.uk](http://www.rnib.org.uk)

Thomas Pocklington Trust: [www.pocklington-trust.org.uk](http://www.pocklington-trust.org.uk)

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## Sensory impairment and dementia

### Alternative Futures Group

Alternative Futures Group are one of the UK's largest health and social care charities, currently supporting around 1,200 people across the UK and employing over 2,500 staff. They work locally in the community and through their treatment and recovery centres to provide a wide range of innovative and bespoke care services delivering life-enhancing person centred support to people with a diverse range of care needs.

#### Five top tips

1. Be clear that we cannot deliver personalised support if we don't know what matters to people and how best to support them from their perspective, therefore a one-page profile is the foundation of personalisation.
2. Recognise that delivering personalised support requires a huge cultural shift in many areas. It's a different way to work together and think about what is going to work for the person being supported.
3. One-page profiles needs to be developed over time.
4. As soon as there is enough information about someone recorded in a one-page profile, we need to ensure we are acting on the information and continually listening and learning so that the one-page profile grows and evolves with the person.
5. Remind people that our quality of life is determined by the presence or the absence of those things which are important to us and so we have to take this into account when providing support.

While on-going research, discussion and debate is taking place with regards to dementia, it is important not to overlook the small things we can do to support people living with dementia to live good lives.

### *In practice*

This case study is about Arthur. He has a recent diagnosis of dementia, is registered blind and does not hear very well. His story supports the premise that if we don't know what matters to people and what 'best support' looks like from the person's perspective we cannot deliver personalisation.

Arthur is 86 years of age and lives in his own flat in an inner city area with a high crime rate. This is an issue for Arthur's family and carers as he tends to go outside in the middle of the night if he becomes confused.

Arthur is terrified of being 'put in a home' so his family and carers are doing their best to help him stay in his own home. He has support from home care workers four times per day to prepare his meals for him. In addition to his sensory impairments, Arthur must have his walking stick within reach as he has quite an unsteady gait. He finds his way around his flat quite easily but his furniture should never be moved around or it could cause confusion and he shouldn't go out alone.

The team supporting Arthur at home began to use person-centred practices - practical tools to help health and social care professionals understand what makes a person tick and which create action for change.

Arthur, his family and a team member sat down and developed his one-page profile through conversation. From those conversations they summarised together what was important to him and how best to support him, and also what others appreciated about Arthur. There was a focus on the positive, valued characteristics of Arthur – his important relationships and connections, passions, hobbies and interests – in so much detail that you know which newspaper he liked.

Much of this could have been overlooked – such as the fact that he wanted his food served very hot and he must always have a £10 note in his top pocket. But when he shared these small details with staff they were able to act on them. The manager worked with all the staff team to make sure that as well as being healthy and safe, what mattered to Arthur was put at the forefront of his care. The staff learned that if he was in bed they should never approach him as he would think it was a burglar and hit out with his walking stick. Calling his name from the bedroom door worked best – but due to his poor hearing, staff needed to ensure he acknowledged them before approaching him.

Arthur always wears his wool bob hat and said he is sick and tired of people telling him to take it off – his view is “this is my flat and if I want to wear my hat I will wear it”. He has lived in his flat for 35 years. He lost his wife Madge 20 years ago and treasures her wedding ring which he wears on his little finger. Arthur loves talking to people and is an amazing storyteller.

They learnt that Stephen is Arthur's nephew who Arthur loves dearly. Stephen phones Arthur every day at 5pm which he really looks forward to. Stephen also visits on Tuesdays and Saturdays and takes Arthur to his house for tea every Friday where Arthur loves chatting to Sally (Stephen's wife) and their teenage children Jo, Ollie and Darren. This is the highlight of Arthur's week.

Arthur makes sense of his days by sticking to his routines; anything out of the ordinary will totally disorientate him, leaving him confused and likely to go outdoors in search of help. He always has a £10 note in his top pocket “in case he needs it”. If he loses it, he will struggle on his hands and knees for hours looking for it. If something out of the ordinary is happening, such as a hospital appointment, staff explain clearly to him about this a week beforehand and remind him daily.

From those conversations there was enough information to learn some of the things that really mattered to Arthur and how best to support him from his perspective. Asking different questions led to different conversations, giving a thorough understanding about what matters to Arthur and how he wants to be supported. This is the information that was needed to ensure his support is tailored to his needs and aspirations.

One-page profiles are fundamental to the planning process and Arthur's profile has become the job description for those providing his support. This helps to ensure these things are present and that Arthur is consistently supported in a way that makes sense to him. This enhances his choice and control on a day-to-day basis. Staff cannot decide on outcomes to be achieved without doing it in the context of what is important to people and knowing how best to support the person from their perspective.

One-page profiles are also a person-centred thinking tool that support the transition from people living with dementia being passive recipients of care, to them being recognised as equal valued members of society. They also herald a new progression, as services aspire to move beyond personhood towards citizenship and personalisation, with a view to enhancing the amount of choice and control people have.

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## Useful resources

[www.coalitionforcollaborativecare.org.uk](http://www.coalitionforcollaborativecare.org.uk)

[www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk)

[www.dementiacarematters.com](http://www.dementiacarematters.com)

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)



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## Sensory impairment and dementia Carers Trust 4all

Carers Trust 4all provides care and support to people with care needs and their carers. The organisation delivers a wide range of services that are tailored to the individual and all care packages are different. Carers Trust 4all has an excellent learning and development programme which effectively supports its workforce to deliver high-quality care in people's own homes.

### Five top tips

1. Make sure your staff team has the tools to do their job – a well-trained workforce that knows what to expect when supporting people with dementia can make such a difference to the quality of care being provided and the ability to be responsive.
2. Good ongoing communication with the training provider (in the case of Carers Trust 4all, this was their training manager) to ensure that training needs are met, especially where a client's needs were changing quickly.
3. Thorough training for the full team around mental capacity, especially around working with the five key principles at the forefront of everything.
4. Develop a process for 'whole family' assessment from the very start when working with someone with a dementia diagnosis and the added complexity of a physical disability.
5. Good sharing methods for the carer support team – regular debriefings worked very well and gave the team a chance to offload and reflect.

While on-going research, discussion and debate is taking place with regards to dementia, it is important not to overlook the small things we can do to support people living with dementia to live good lives.

### *In practice*

This case study is about Mr and Mrs L who lived in the family home. Mr L was 95 years of age and had been diagnosed with clinical depression with auditory hallucinations. He had very poor mobility and spent a large portion of the day in bed. Mrs L cared for her husband and provided a great deal of emotional support to him. She had a diagnosis of Alzheimer's and was registered blind.

Mrs L was displaying signs of memory loss, in particular with short-term memory. She was struggling with remembering if she had taken her medication and if she had helped her husband take his. Mrs L's husband was unaware of her diagnosis as she didn't want to worry him and she had full capacity to make her decision. Mr and Mrs L's family lived 150 miles away but visited every other weekend and were very supportive and involved.

Several weeks after the diagnosis, Mrs L suffered a serious fall at home causing a broken leg and concussion. She spent five weeks in hospital and a further three in a rehabilitation centre.

During this time Mr L moved to his son's home. Whilst there, he began taking his medication correctly and ate regular meals which saw his weight increase, something the family had been concerned about. His motivation also increased and he became more interested in self-care.

When Mrs L was ready for discharge there were some lengthy discussions about what would be the most appropriate outcome. All professionals involved felt very strongly that she should go into a residential care setting which also meant that her husband would either need to move in with his son full-time or go into residential care himself.

Both Mr and Mrs L were determined to stay together in the family home and it was agreed that it would continue if they accepted some help. This was when Carers Trust 4all first met Mr and Mrs L. The family and professionals felt that a care and support package should include meal preparation, cleaning, medication administration, washing and other household tasks. It was also felt that Mr L needed full support with personal care, something that Mrs L was resolutely against. She felt that as she had managed for years, she should be able to continue.

A care package was developed with Mrs L's dignity and pride at the centre. Carer support workers took on tasks that Mrs L found onerous or forgot to do to allow her plenty of time to help Mr L have a wash and get dressed. The carer support worker was always on hand should Mrs L need help but it was always on her terms.

The support team only consisted of three people who were experienced in supporting both people with dementia and those not very accepting of care. Because of this, Mrs L slowly got used to having people in her home.

The family supported this transition by talking to Mrs L about the carer support workers. Photo rotas were also provided to help Mr L see who was coming in and at what time so he could remind his wife.

Initially, it was very difficult to establish the right time to visit Mr and Mrs L because of Mrs L's worsening dementia. The carer support workers would frequently find that she had already made breakfast and they would find tablets on the floor indicating she had tried, and thought she had succeeded, to give her husband his medication.

The impact of the combination of Mrs L's visual impairment and dementia often meant that Mr L didn't eat a full meal, or had insufficient portion sizes. Because of his depression and desire not to have contact with anyone, he would always say he had eaten or was full when carer support workers offered to make him something. He refused to be weighed so it was not easy to tell if he was losing weight. Mr L sometimes said he "played tricks on his wife" because he knew her memory was poor. He would tell her she had given him his medication or he had already eaten when he hadn't and Mrs L either wasn't able to remember clearly herself or wasn't able to see evidence of eaten food or that his tablets had been taken.

It was quite some time before the extent of this was recognised. It was through the carer support workers giving their care coordinator clear and regular feedback, and in turn the care coordinator regularly talking to the family, that it became clear that the care package was no longer enough.

A number of reviews were held where social workers looked at how safe both Mr and Mrs L were in their home. It was agreed that because of their unwillingness to accept more than minimal help and support, that they would not be able to stay in their own home. Carers Trust 4all supported Mr and Mrs L to make their wishes to stay together known and a small one-bedroom flat was found with a 24-hour warden.

The case study highlights the complexities of supporting someone with a sensory impairment and dementia. It also highlights the need for a whole family assessment as at the start, Carers Trust 4all were informed that it was just Mr L with support needs, when in fact both Mr and Mrs L needed support.

The organisation did feel that there was a lack of understanding of supporting someone with dementia who was a carer in the wider social care community. This could be addressed with some good awareness raising sessions delivered to a much wider audience such as the Dementia Friends initiative offered by the Alzheimer's Society.

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## Useful resources

Alzheimer's Society factsheets – for carer support workers to use as a reference tool  
[www.alzheimers.org.uk/factsheets](http://www.alzheimers.org.uk/factsheets)

Skills for Care – Common Core Principles for supporting people with dementia  
[www.skillsforcare.org.uk/dementia](http://www.skillsforcare.org.uk/dementia)

Mental Capacity Act – Easy read guide  
[www.alzheimers.org.uk](http://www.alzheimers.org.uk)



## 4

## Holistic care for people with dementia and other conditions

### Angelica Place, Manor Court Care

Angelica Place has a goal to provide a high-quality, flexible seven-hour therapeutic day-care service for those individuals who currently live within the community.

Angelica promotes individual's independence at all times. The service is staffed seven hours a day by specialist trained staff who use therapeutic activities with the primary goal of supporting self-expression and communication among the people using the service. Angelica Place provides an enjoyable and sociable day out from home. It provides an opportunity for individuals and staff to make new friends and enjoy regular social interaction.

#### Five top tips

1. Believe in the therapeutic activity you are preparing to deliver; it might not work for everyone initially, but you will recognise that small parts of an activity make big differences.
2. Create a workforce culture which sees the person first and the dementia second. An effective way of developing this culture is to use your dementia champion as an 'on-the-spot' trainer alongside the in-house training.
3. Remember that honest and heartfelt self-expression is unexpectedly powerful in building relationships with others.
4. Empower the staff to recognise that self-expression requires freedom – freedom to communicate and act in a relaxed environment without restrictions laid upon individuals.
5. Ensure there is an ongoing commitment to communicate with staff, relatives and carers to create an atmosphere of holistic care which is acceptable to all.

While on-going research, discussion and debate is taking place with regards to dementia, it is important not to overlook the small things we can do to support people living with dementia to live good lives.

## In practice

Angelica Place has four main priority areas in ensuring the correct delivery of therapeutic activities within the spectrum of self-expression and ensuring good communication:

- to provide a range of acceptable therapeutic activities
- to acknowledge the right of every individual to achieve their full potential, however small, and to realise their personal aspirations, even where this may incur a degree of calculated risk
- to provide a clear person-centred care plan which all individuals can work from together
- to promote the right of every individual to be recognised for their unique value as a person; for their personal status to be acknowledged, and to be treated with dignity and respect at all times.

To show how these four points are achievable, Angelica has described some of its therapeutic activities below:

- The therapeutic activities are diverse and range from pamper sessions, animal visits, cooking their own lunches and a book reading group to workforce groups (including gardening, men's maintenance and a ladies work group).
- Within Angelica's men's workshop group, the men have built a post-box for the Christmas mail, bird boxes and are currently refurbishing small card tables.
- Angelica holds extended exercise classes every Thursday and every other Wednesday.
- Angelica's sensory room is available for those who will enjoy the sensory objects within it and who are able to access its location. However the staff at Angelica also accommodate individuals who want to take part in a sensory session without moving away from the main group by setting up small group sessions near to the main group, using the moveable objects from the sensory room.
- Angelica's gardening group has raised vegetables boxes which, when mature, are supplied to the kitchen for inclusion in their meals. The garden has a washing line so the Angelica ladies can hang out their washing. The garden has bench seats for afternoon tea, surrounded by the smell from the aromatic plants.
- Angelica music sessions range from sing-songs with musical instruments to an entertainer blasting out 1950s and 1960s music.

Therapeutic activities can be as small or as big as the people using the service dictates. Small activities such as pamper sessions can include three or four people, while in other activities, such as group musical entertainment all the group can join in by dancing, singing along, or tapping feet and fingers while others play instruments. Within the Angelica workshop group some of the men have been involved with a complete construction project while others prefer to dip in and out as they feel their skills are needed. The Angelica extend group holds their sessions in the 1950s living room. These are based sitting down and are full of music, movement and laughter.

Angelica's staff recognise that activities are not set in stone and can be delivered in a different way, or at a different time. They also recognise that activities are not always for everyone and if something isn't working Angelica staff can change it.

Each individual has their own identity and this is recognised by the staff team at Angelica Place who review practices and implement changes accordingly. Angelica's care staff are skilled in the provision of maintaining therapeutic activities in a positive and sensitive way; in meeting all physical, psychological, spiritual and social care needs, as well as individual needs.

Each individual will have a person-centred care plan. This plan is only built up through consultation with the individual, family members, outside agencies and any other relevant parties. Priority thoughts, ideas and working life, alongside likes and dislikes come to the fore within this plan. From the information held within the plan, the daily therapeutic activities can be reviewed and implemented to each individual on their own level and acceptance.

Key principles of good practice at Angelica Place include:

- encouraging and believing in building positive relationships. In building these relationships they recognise acceptance, respect and honesty; all positive outcomes
- providing a support network which is positive in both its social and physical boundaries
- maintaining a good level of dialogue with individuals and their families/carers around the therapeutic activities which they would like to see delivered. Respecting boundaries set up by the individuals taking part
- listening to individuals who want their voice to be heard around therapeutic activities
- having an ever-evolving calendar of therapeutic activities.

Angelica involves outside people in the care planning stage to gain as much information as possible. By doing this Angelica ensures a good foundation on which to build a tailor-made therapeutic activity service. The service can then change with the individual as they experience their own changes while on their dementia journey.

It is important to recognise that positive outcomes are different for each person, are on a different level and that some people with dementia do not always recognise their own outcomes.

For all of the therapeutic activities to deliver on a spectrum of self-expression and a good level of communication, the Angelica staff work together as a team from the management through to the kitchen staff. By working together as a team, the staff understand what each activity can achieve; they can also see where the activity delivers a positive or negative outcome.

With such a strong integrated approach Angelica has a very stable workforce, which is committed to a wide spectrum of self-expression and communication for all those who they meet along their own journey, working with individuals who live their own lives within their dementia.

One-page profiles are a person-centred thinking tool that support the transition from people living with dementia being passive recipients of care to them being recognised as equal valued members of society. They also herald a new progression, as services aspire to move beyond personhood towards citizenship and personalisation, with a view to enhancing the amount of choice and control people have.

# 5

## Learning disabilities and dementia Hull City Council

Nicholson House in Hull currently provides specialist care for both permanent and respite individuals. Their primary focus is supporting people living with advanced complex needs due to diagnosis of dementia. They also support a small number of individuals with a learning disability.

### Five top tips

1. Improving wellbeing can improve health.
2. Support the whole person rather than treating the illness.
3. Consistent person-centred approaches build relationships and trust.
4. One act that achieves a smile is an isolated incident, shared, it can become a daily occurrence.
5. A meaningful goal is only achievable with the right attitude.

Care plans are living documents that are changed and added to according to the choices and changing needs of the person, regardless of the diagnosis. Identifying the onset of dementia in a person living with a learning disability can be difficult without medical intervention.

### *In practice - Joan*

Joan lives with a dual diagnosis of a learning disability and dementia. She has lived in residential care for 51 years. She was diagnosed with a learning disability and lived alone with her aging mother. When her mother required full-time care it was felt it would be appropriate for Joan to accompany her. Joan was 37 years old; she is now 88. In her later years Joan began to show signs and symptoms of early dementia, although many of these actions mirrored Joan's habits and routines of earlier life, making a diagnosis uncertain.

Through the Dementia Academy, staff received sensory training enabling them to provide people with a personal journey using the five senses of sight, sound, touch, feel and taste. By implementing the training they immediately observed overwhelming positive changes and reactions from the people they care for.

The Dementia Academy works alongside carers to help improve the quality of life for people living with dementia. A process called 'dementia care mapping' is used and this involves observing a person with dementia over a set period of time and then documenting their experience of approach, interaction and care. Following analysis and the interpretation of the information gathered, the organisation is able to work together to promote and achieve change and improvement in our collective approach to an individual's personalised care.

The staff at Nicholson House then set out to create this throughout the whole of their environment. They start the journey by looking at meaningful activities for each individual, receiving information from life story work undertaken with family and friends and also information and knowledge they have collected over the years. With this information they produce individualised plans of care. These include an individual activity profile, in which they blend the personalised information received and the psychological needs of individuals, such as comfort, attachment, occupation inclusion and identity, to achieve and enhance wellbeing. Using this approach the staff have created an object-rich environment and a 'lived in' feel. They have also created themed areas which provide stimulation through reminiscence and emotion.

Establishing this environment gave Joan purpose, her daily routines progressed from mundane habits to engaging in meaningful activities which supported wellbeing and provided purpose.

### *In practice - Bill*

Bill joined Nicholson House directly from home; he lives with a diagnosis of dementia. Bill's diet was a cause for concern with drastic weight loss and suppressed appetite. Isolation was a fear as he did not want to join in with others and due to this he spent much of his time with one-to-one supervision.

After building a relationship with Bill, the staff began to have a better understanding of his needs. Bill craved reality and normality, his experience of communal residential living forced the staff to look intensely at their environment. It appeared institutionalised; high levels of risk management were in place and the environment appeared empty and clinical. People had nothing to look at but each other. It must have been very confusing to a person living with dementia.

With this in mind Nicholson House created an 'open all hours' café which has music playing in the background, flowers on the tables for people to touch and smell, and newspapers are bought daily which helps people remain in the present. The café is situated adjacent to the kitchen servery hatch which is staffed from 7am – 6pm. It promotes independence, diet and fluids, inclusion and occupational tasks. It is a self-stimulating area.

Bill visits every day, spending long periods of time bantering with staff and other 'café customers' - his weight has increased and his appetite has improved.

Nicholson House's approach to people's needs would be no different if they possessed a different or dual diagnosis. They concentrate on the person, focusing on and celebrating ability as well as understanding the 'unmet' need, working together to increase wellbeing and improving people's quality of life.

The staff are trained in the person-centred approach to care. As a staff team they meet to ensure information is shared and acted on. Staff are either designated 'dementia detectives', who look for areas where they can improve and increase people's wellbeing or 'dementia champions' who look for solutions.

Staff work from 'individual profiles'. These break down each section of care using collated information and life story work to provide a step-by-step tailored explanation of how to best approach and achieve the task ahead. Person-centred profiles encourage a consistent approach to individualised care.

Throughout the building there are themed areas, all of which are designed to create and stimulate the senses. These areas are accessible and were created to encourage participation through conversation, reminiscence and occupational tasks.

At Nicholson House, staff and relatives feel lucky and excited to have recently been chosen to pilot the Namaste programme in the Hull area. The word 'Namaste' means 'the spirit within' and the programme focuses on sensory experiences for people who are most disabled by dementia. They have created a room within the care home which is exclusively dedicated to Namaste care and which hopes to improve wellbeing further.

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## Useful resources

Dementia Academy [www.dementiaacademy.co.uk](http://www.dementiaacademy.co.uk)

Namaste Care [www.namastecare.com](http://www.namastecare.com)



## 6

## Long-term pain management and dementia Making Space

Making Space is a national charity and provider of adult health and social care services. It has been helping adults with care and support needs, and their carers, to lead independent and fulfilling lives for more than 30 years.

Making Space provides high-quality, person-centred services and accommodation, and supports adults of all ages, with a diverse range of needs including mental health conditions, learning disabilities, dementia and older people with age-related conditions.

Admiral Nursing became a part of the service provision in 2012 and leads a central dementia team across the organisation to develop the dementia workforce and provide consultancy to families on complex issues across the disease trajectory. Pain management is one of the areas of special interest for the team.

### Five top tips

1. Ensure that regular checks and reviews are made for people with dementia who are prescribed opioids - in particular those that are housebound.
2. Consider pain from a biopsychosocial perspective.
3. Use the most appropriate pain assessment tool for people who struggle to communicate (this will be different for each family).
4. Involve the family in the management plan and provide education and coping strategies.
5. Develop a simple 'assessment of pain behaviours' tool for staff to use; everyone has a role to play in preventing pain.

### *In practice*

This case study is about Mr A, caring for his mother, Mrs A, with a diagnosis of Alzheimer's in the more advanced part of the illness. He has been sole carer for several years and was experiencing concerns about her deteriorating physical health, in particular, constant pain.

Following an initial biopsychosocial pain assessment with the family, it became evident that there were two key areas that required attention in order to develop a comprehensive management plan to address her total pain issues. Firstly, her physical pain was as a direct result of inflammatory pain in her shoulder caused by osteoarthritis. Additional pain was caused by irritable bowel syndrome and exacerbated by the combination of prescribed medications that had not been reviewed for some time.

Mr A had full responsibility for managing Mrs A's pain on a day-to-day basis, without education or a non-pharmacological intervention. That role became a burden to him and he struggled to cope, impacting their quality of life as a family.

To address these two key needs, the Admiral Nurse reviewed the Assessment of Pain in Advanced Dementia tools to determine the most appropriate to use for the family. This was to ascertain Mrs A's level and intensity of pain on a daily basis. Her level of cognitive impairment was an additional complication, with little communication and some adaptive behaviour. This lack of ability to communicate is a substantial barrier to pain assessment.

In this lady's case it was important to find a tool that differentiated between physical pain and emotional distress. The Disability Distress Assessment Tool (DisDAT) was chosen following the review of what was available. The DisDAT tool identifies distress as the primary factor, with pain being a single part of the whole picture of distress. Other distress factors being identified as environmental and poor perception of situations. In the case of Mrs A, the distress tool would be of more relevance as she shows signs of agitation and emotional distress on a regular basis. Being able to differentiate between these would be inherent in the future management and treatment plan.

Information taken from this assessment was then used as evidence in the multi-disciplinary review process to inform the family-centred pain management plan.

In addition to this, the Admiral Nurse explored the emotional impact of chronic pain on her son in his caregiving role and whether his hypervigilance (preventing her from standing) and fear avoidance behaviours (not going out of house) were causing unnecessary limitations to their lives. This provided the basis for an activity and education plan to reduce his burden and introduce non-pharmacological treatments into her care.

Evidence available around this area suggests that Mr A has developed new strategies for preventing recurring injury. Unless this is addressed with a plan to expose them to new situations, under skilled and careful support from professionals, they will continue to live with a poor quality of life and constant fear. A plan to work with the carer to expose the family to situations that they have previously avoided should help him to build confidence in their abilities to explore the outside world, restoring their connection to others.

A plan was put in place with support from the multi-disciplinary group involved in Mrs A's care and over a six-month period, there was a reduction in her pain levels (this was evident in the repeat use of the assessment tool at two weeks, one month and three months). Her carer reported improved confidence in carrying out daily activities but also in getting her out of the home for recreational and support group activities.

Initially, a minimal pharmacological plan was in place. The updated plan aims to draw professionals together to manage Mrs A's care with the Admiral Nurse taking the lead in co-coordinating this. The Admiral Nurse wanted to build the confidence of Mr A so that something can be done and that he has reliable parties involved that will both enable him to make decisions and support him in those. Following the period of intensive work with the family, he stated: "I know we can trust people now and that I can try to take on board what others say. We are not destined for failure"

This case study highlights how important it is for the families of those with dementia to be supported in coping with pain. There are many things that can be done to alleviate distress for the family if consideration is given to the biopsychosocial model, while also including spiritual pain such as coping mechanisms and addressing the needs of carers. This can be achieved through advice, support and education as part of an integrated plan to improve their quality of life as a family.

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## Useful resources

The National Council for Palliative Care (2012) *How would I know? What can I do?* publication explains how to help someone with dementia who is in pain or distress and is available from [www.ncpc.org.uk](http://www.ncpc.org.uk)

National Institute for Health and Clinical Excellence (2006) *Dementia: Supporting people with dementia and their carers in health and social care* (CG42) [online] London: SCIE available at: [www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf](http://www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf)

Royal College of Physicians, British Geriatrics Society and British Pain Society. *The assessment of pain in older people: national guidelines*. Concise guidance to good practice series, No 8. [online] London: RCP, 2007 Available from: [www.britishpainsociety.org](http://www.britishpainsociety.org)



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## Parkinson's and dementia Cardinal Healthcare Group

Cardinal Healthcare Group delivers a personalised range of services at their residential care homes in Suffolk. The group comprises of two care homes and also offers care in the home through Primary Homecare. The care homes offer residential and nursing home care in Suffolk, as well as specialising in day care, short-term rehabilitation, convalescence, respite and dementia care.

### Five top tips

1. There needs to be a whole team commitment to the ethos to 'care for the person before the disease'. The plan of care should be totally unique and detailed so everyone should recognise the person, without looking at the name.
2. Communication - all staff to embrace positive interactions with both resident and relatives. Really listen and observe - remember not all family expectations match.
3. All staff to receive training on empathy and compassion - but equally important is observational supervision to assess the impact of learning and competence on the job.
4. Empower staff to be courageous – to think 'outside the box', to be flexible, to go the extra mile. The whole team must be part of developing a relationship-centred service.
5. Create a sense of possibility and opportunity, even for long-term conditions – everyone needs to contribute to achieving individual goals and aspirations, however small.

Facing the prospect of dementia and a long-term illness is difficult and life changing, even more so when families decide it's no longer possible to continue care at home.

Understanding the emotions at the core of this transition is why Cardinal Healthcare has changed its approach and commitment to families from the initial enquiry. By placing more emphasis on seeing the 'person before the disease', the aim is for people to feel better about their home and their life - their way. This can be achieved by empowering residents and their families to get more involved in the home – for example; by meeting staff, spending time in personalising bedrooms and by creating a memory box. The challenge then is to ensure all staff are on board and share the challenge to maintain that positivity and create opportunities for every person with a long-term illness, incorporating their aspirations, wishes, personal and family goals in their plan of care. Staff are reminded that we all need to feel part of a family.

## In practice

This case study is about Mr B, who has a diagnosis of Parkinson's disease and Lewy body dementia, and his family and how Cardinal Healthcare's 'relationship-centred' approach has impacted on their wellbeing, care and support.

The usual pre-admission assessment encompassed the activities of daily living. Cardinal Healthcare concentrated more on getting to know Mr B and his family from all their perspectives - past, present, their fears and aspirations - not just what the social worker report or hospital discharge letter said.

Discussing the past and how their relationships had been strained by caring brought forth a number of emotions from the family. These included tears, anger and the distrust the family felt in what they perceived to be 'care' within care homes, as they had seen on the TV.

As part of the pre-admission process, staff actively listened and highlighted key words the family used. The words said with more emotion were perceived as carrying greater importance to the family and it was those actions and expectations that Mr B's care plan was built around.

Cardinal Healthcare believes building a bond with families and a mutual trust is most important, the focus being on embracing a relationship (between resident, relatives and staff). By listening to everyone's expectations and considering risk, staff are encouraged to be courageous with care and be open and honest about aiming to meet everyone's expectations.

The following gives an insight into what Mr B and his wife Mrs B said, using the 'This is Me' tool:

- Married for 65 years: "In our day, marriage was for better or worse!"
- Mr B always got up early at 05.45. Washed and dressed before breakfast. Mrs B stated - "Mr B has always been particular about his appearance, always clean shaven. It's difficult now as he doesn't understand that I'm trying to help him."
- "I hate it now he dribbles."
- "He would love a shower or bath as he can't have one at home."
- Mr B was in the army for five years, he then had a career with BT as an engineer. Mr B said that "he will rewire, connect phone lines and plugs while he is here".
- He used to enjoys quizzes and puzzle books, although can't do them anymore.
- He used to like walking his dogs and going on walking holidays.
- Mrs B said medication was important, "the timings have to be exact. I give them to him on a spoon with yoghurt."
- Mrs B said she would like carers to try using conveyers during the day, so they could go out.

Setting the bedroom up in preparation for Mr B's admission was important as part of the admission process, but the innovation was going the 'extra mile' in the person-centred approach. For example, asking the couple to bring in Mr B's boot scraper for outside his door, along with his old walking boots, hat, and dog lead to hang up on a hook outside, ready for a walk.

Pictures were hung on the wall and a memory box filled with conversation starters, for example who's who, dates and information – which created important reminiscence tools.

A clothes protector was also supplied. This was a backed shirt front, modified to be just the front and worn over Mr B's clothes so it could be changed easily and didn't stand out as being a clothes protector. Suddenly Mrs B said "going out to eat with her husband would no longer be as embarrassing," as the dignity protector looked "just like a normal shirt".

Staff went on to create opportunities for Mr B to mend old kettles, and supplied wires, old sockets, plugs and even his old boiler suit to wear. A part of his routine became stopping for 'elevenses' with the maintenance team. All the usual risk assessments were put in place, as part of evidencing the duty of care, but by concentrating on looking holistically at the whole family, as well as the healthcare needs of Mr B, suddenly the family dynamics changed. Relationships were repaired as the family were no longer simply stressed carers, but a wife and daughter again.

Mr B and his family added a new dimension to the home and the centre life, really joining in, spending time together. Even if Mr B was asleep the family would stay and join in with team quizzes, supporting other residents and being supported themselves by a wider group of people.

Examples of good practice:

- Create positive social interaction for the whole family and team.
- Stimulate reminiscence with 'pockets of opportunity' that's meaningful to the individual.
- Engagement in everyday life - even if Mr B could no longer do a quiz, joining a team quiz gave the same feeling of participation and inviting his family to make the team was even more positive.
- Key workers spend time with families to build a life story into the care plan and supporting all parties in understanding and improving communication and quality of life and maintaining it in the review meetings.

In understanding that relationships suffer too when someone is chronically unwell and has dementia, and by placing more emphasis on building a 'relationship-centred service', there has been a tangible enhancement on everyone's wellbeing. Improvements can be seen in the individual's sense of possibility, a reduction in antipsychotic medication, the team's morale and the support to both residents and their families and in the contributions to 'home life' that families have made. Families have reported increased confidence and trust in staff and there is an increased desire by everyone to contribute to ideas and suggestions.

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## Useful resources

UK wide initiative promoting better quality of life in care homes [myhomelife.org.uk](http://myhomelife.org.uk)

A national network of dignity champions [www.dignityincare.org.uk](http://www.dignityincare.org.uk)

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## Mental health and dementia

### Rethink Mental Illness

Reconnect is a part of Rethink Mental Illness and is a service which has been offering housing related support since 2002. The service provides high quality client led support and aims to support clients to stay safely in their own homes and live independently for as long as possible.

The Reconnect Service is funded by Somerset County Council, it is free to residents of Somerset and is delivered by a floating support model -Support workers visit once a week, generally, and work with the client to achieve the goals agreed with them in their support plans..

#### Five top tips

1. Recruit staff on a basis of values and competencies.
2. Good staff training and support.
3. Allow staff time to build rapport with the person being supported.
4. Treat staff as professional experts, value them and listen to their feedback.
5. Set clear support goals that are measurable and time limited.

### *In practice*

This case study is about MB. He was referred to Reconnect following a hospital admission for a fall. His wife had died six months previously and he had just had his driving licence withdrawn. While in hospital, ward staff had noticed his memory loss and that he was having trouble finding his words, although this improved with medication. He also had a diagnosis of paranoid schizophrenia. He was slightly unsteady on his feet and had a diagnosis of spinal spondylosis which caused him neck pain.

MB's support needs were assessed with him at an initial needs assessment. The difficulties identified were:

- managing dementia and paranoia
- managing mail and correspondence
- feeling negative about his doctors
- remembering what the GP had said to him and what he needed to talk to the GP about
- muddling his keys
- getting to his garage safely

- accessing services such as a handyman
- talking on the phone
- conversing with men
- remembering appointments
- remembering medication
- remembering to have a daily hot meal
- attending activities on his own
- joining in with other people.

Research was undertaken to give informed choices to MB. Time was taken for discussions, ensuring that MB felt valued. A person-centred approach with respect was given at all times. Responsibilities were given back to MB, through his involvement with the Reconnect service and his feedback was valued.

Staff spent time getting to know MB; building trust and rapport with him. It had been identified at the initial assessment that he needed support with safety in the home, managing his paperwork and support with monitoring and maintaining his health.

MB was paranoid about his doctor. This was discussed and his reasons were listened to. He was given information on how to change his doctor. A list of local GP surgeries in the area that were accessible to MB was compiled and MB chose his preferred doctor and the worker supported him with registering. The support worker discussed with him how he could remember the reason why he was attending the doctor and what was said by the doctor. MB started writing down what he was going to see the doctor about and the GP agreed to give MB a printout of the outcomes of the visits. The GP referred MB to a physiotherapist to help with the pains in his neck.

Support was given to complete a home safety check and adaptations were discussed, agreed, applied for and completed. During the check, the Rethink support worker was present and wrote down all concerns which were then actioned jointly by MB and the support worker. As part of this process MB was given information about the handyman service and was supported to arrange an appointment for a grab rail to be fitted to the outside steps to the garage. In addition, the freezer that had been in the garage was moved into the spare room for easy access and an extension was put onto the phone wire to enable MB to use the phone in comfort, rather than standing in the hallway. He was also supported to use the council's larger item home collection service to dispose of large unwanted items.

MB had been getting very confused about his house keys, often losing them or being confused about which keys were for which door. To stop this confusion, the keys were colour coded with permanent colour markings.

MB was introduced to an orientation clock and linked it with a calendar to help him remember his appointments.

His mail was sorted and his late wife's savings were transferred into his account after he was given support to get a copy death certificate as the original was lost. Bills were put onto direct debit and cheques were written out and posted. This was achieved by the worker reading out the mail to MB and discussing what to do with it. This support was on-going throughout his time with the service.

MB started showing more paranoid thoughts. The doctor did not want to prescribe medication as the medication could worsen the dementia. Other methods of how to combat his paranoia were discussed and they decided together that social inclusion and activities may help to distract MB from the things that were playing on his mind. The support worker researched local activities and introduced these activities to MB. It was agreed with MB that the worker would attend with him for the first three times and then the worker would withdraw and MB would attend on his own. When this was put into practice, MB stopped going after a couple of times on his own. This was discussed with MB and he agreed to pay for a person to attend activities with him on a one-to-one basis. A befriender was introduced and it was arranged for the befriender to take MB out once a week and join in with social groups. MB enjoyed this so it was agreed for the befriender to take him out twice a week. Sometimes they went shopping, to the hairdressers, to singing for the brain sessions, on walks or visits to garden centres.

Other support given as the dementia worsened included:

- information and introduction to community transport
- medication put into blister packs and delivered

Being flexible with time enabled MB to deal with issues that were important to him and his safety thus enabling MB to stay in his own home for as long as was possible.

MB had two Reconnect workers; one worker to deliver the support and one to review his support needs and this provided continuity of support.

As the dementia advanced, the paranoia worsened and MB felt that people were out to get him. He believed that people from TV were real and they wanted to steal his home. He then started thinking that home care service staff were planning to poison him and refused to eat or drink at times. He started raising his voice at his neighbours. The only people he trusted were the Reconnect worker and the befriender. The Reconnect worker communicated her concerns about MB's health and wellbeing. His GP referred him to an in-patient ward where he stayed for a few weeks. It was decided that he was too ill to go home as he would not be able to manage at home so he went into a care home.

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## Useful resources

Age UK - [www.befriending.co.uk](http://www.befriending.co.uk)

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## Specialist dementia and learning disabilities learning Freemantle Trust

The Fremantle Trust is a registered charity and not-for-profit business providing care and support services for older people and adults with a learning disability. In operation since 1992, The Fremantle Trust has homes and supported living services in Buckinghamshire, Barnet and Harrow, Maidenhead, Milton Keynes and Bedfordshire. In total over 1,700 staff provide services to almost 2,000 people.

### Five top tips for other managers

1. Consider a specialist development pathway using the Qualifications and Credit Framework (QCF) units.
2. Engage managers in the development and delivery of all programmes.
3. Have a champion or lead for particular areas of specialisms.
4. Devise interactive workshops to deliver learning in 'bite-sized chunks' – keep it simple.
5. Encourage staff to identify their own preferred learning styles.

### *In practice*

This case study sets out a novel approach to specialist dementia and learning disabilities learning developed by The Fremantle Trust's Development and Education Centre.

Initially designed for staff working with older people, the approach recognises several truisms:

- Working in care homes for older people in the UK means working with older people who have dementia – it's a specialist area of work that needs to be embraced.
- Staff have limited time and opportunity to develop skills and learning in non-mandatory subjects - often staff are trying to fit learning in outside their normal duties.
- E-learning about dementia is available but hasn't met the needs of staff who develop understanding through discussion and practice.
- Staff prefer learning in 'bite-sized' interactive workshops not classroom-style settings.
- The qualification pathway for dementia can be academically demanding and intimidating for a workforce comprising staff who do not see themselves as 'scholars'.

Following initial induction and mandatory training, staff at Fremantle Trust have been offered a mix of dementia learning opportunities. These include:

- dementia induction using an in-house manual and one-to-one sessions with a dementia advisor
- a qualification pathway using the Level 2 Award in Awareness of Dementia (QCF)
- expert speakers at The Buckinghamshire Dementia Forum, created and hosted by The Fremantle Trust
- a suite of 12 in-house specially designed training sessions/workshops (since 2012)
- online opportunities provided by the Aged Care Channel (since 2014).

Out of all of these, the in-house sessions were regularly used while the BTEC qualification was the least used. In fact the drop-off rate for the qualification was high, with staff quoting various reasons for being unable or unwilling to continue. For example, the fact that they felt that they had no 'quick wins' and were isolated from other learners.

To redress this imbalance and to regenerate enthusiasm for the qualification, the Fremantle Trust's practice lead in dementia revised the existing Level 2 Award portfolio and devised a new, time-limited programme.

The revised BTEC in dementia course is structured to be completed within a four-month timescale. Groups of 10 staff are formed working in the same geographical areas with four groups in each cohort. Each of the units of the qualification is supported by a specific workshop that addresses the following topics:

- dementia awareness (QCF DEM 201)
- the person-centred approach to the care and support of individuals with dementia (QCF DEM 202)
- understand the factors that can influence communication and interaction with individuals who have dementia (QCF DEM 205)
- understand equality, diversity and inclusion in dementia care (QCF DEM 207).

Within the workshops, the objectives of the course assignments for each unit are explored; staff get the chance to openly discuss issues, debunk myths, air problems and share successes. Inevitably they learn from each other as well as from the workshop leader, a specialist dementia trainer. Staff are issued with a 'refreshed' portfolio that has a pleasant, bright layout and imagery, making it a welcoming and attractive read. Extraneous materials are removed to reassure those who may be daunted by weighty, serious looking 'tomes'. An up-to-date 'resources and materials' section is included to guide access to relevant, authoritative information.

Assessors from within The Fremantle Trust are offered an 'assessor's guide' to support them in their role and also to provide consistent assessment and quality assurance across the programme. Assessors have also undertaken this qualification.

While developing this programme, including the portfolio and workshops, it became apparent that the model could be replicated for other qualifications, specifically the Level 2 Award in Supporting Individuals with Learning Disabilities. With that in mind, staff from the Development and Education Centre and specialist learning disability staff used the portfolio template to create a new learning disability portfolio and to accompany this, specific workshops were created for another cohort of staff eager to follow the programme.

The Fremantle Trust finds that the model for this programme works because timescales and deadlines for the workshops and completion of assignments are set. This maintains momentum and gives group support. Because the programme is divided into four sections, staff can easily see their progress – creating a ‘quick win’. Staff are motivated to do a qualification that is ‘manageable’ but also recognise the value in these certificates, awards and units in contributing to a full diploma at a later stage.

Some of the evaluation comments gathered about the programme include that:

- it has ratified what staff thought about dementia knowledge and practice
- it has given staff confidence to challenge others whose practice falls short
- staff feel that they can justify sitting down with residents and engaging with them
- managers report an increase in staff knowledge and competence.

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## Useful resources

Joseph Rowntree Foundation – *Supporting Derek*  
[www.jrf.org.uk/publications/supporting-derek](http://www.jrf.org.uk/publications/supporting-derek)

# Skills for Care resources

*The common core principles for supporting people with dementia (2011).*

*Better domiciliary care for people with dementia; Best practice case studies from domiciliary care employers developing their workforces to support people with dementia (2014).*

*Dementia and carers together - A guide for social care workers on supporting the family and friends of people with dementia (2012).*

*Dementia and carers: workers' resource - Information for care workers supporting the family and friends of people with dementia (in partnership with Dementia UK) (2012).*

*Supporting dementia workers A case study-based manager's guide to good practice in learning and development for social care workers supporting people with dementia (2012).*

*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 (2013).*

All these resources can be downloaded at [www.skillsforcare.org.uk](http://www.skillsforcare.org.uk).



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