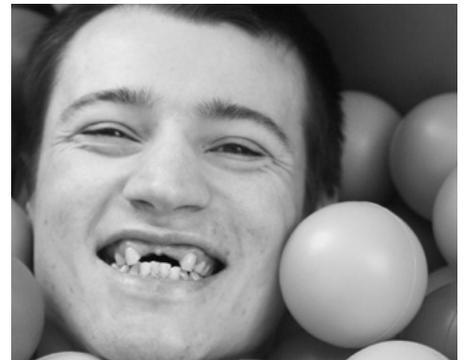


Better domiciliary care for people with dementia

Best practice case studies from domiciliary care employers developing their workforces to support people with dementia



Preface - Sharon Allen, CEO

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 domiciliary services that are providing care and support to people with dementia. The guide supports leaders and managers in developing their workforce to enable them to provide the highest quality of care in home care 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 supports managers to undertake values based recruitment of home care staff, ensuring they are motivated, and supporting staff who are working with people with dementia whose behaviour may challenge.

In addition the also guide covers working with carers to support the person with dementia, facilitating and enabling meaningful activity and supporting end of life care as well as other 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.



Sharon Allen,
Chief Executive Officer, Skills for Care

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1 Supporting new staff into the homecare sector and addressing misconceptions about dementia

Five top tips for managers:

1. Make dementia awareness training part of every new employee's induction process.
2. Do not overwhelm new workers with huge amounts of statistics – provide information in digestible sections.
3. When training more than one new worker, understand that they will have different learning needs.
4. Provide continuity of care for the person with dementia, this will enable new workers to build a solid foundation with them.
5. Incorporate different training techniques, ranging from group training sessions to on the job training.

Quality Care Home Services Limited is an independent care provider that has been providing domiciliary care for 15 years. They pride themselves on the standards of care they provide to the people needing home care by their team of well trained, experienced staff. They are particularly proud of the training and support they offer new recruits to the company, many of whom have no previous experience in the care industry. This training and development is in all areas of home care but particularly around caring for people with dementia.

As two thirds of all people with dementia live in their own home, either alone or with family carers, it is vital that domiciliary home care providers are able to demonstrate good practice by ensuring that all new employees receive training and on-going support. The training and development received will enable workers to easily identify any difficulties that they may encounter while providing care and support to people with dementia.

Quality Care understands that it has a duty of care to provide a level of care which meets the needs of people needing care and support but one which also provides support to family carers.

Employees are invited to take part in a three day training course entitled 'Tomorrow is Another Day', held by Oldham Development Academy. Upon successful completion they receive a

Foundation Certificate in Dementia Awareness issued by the Alzheimer's Society. Following this, staff keen to develop their skills further in the field of dementia are invited to become 'dementia dignity champions'. The nominees are interviewed by the Development Academy to assess their suitability.

Successful applicants attend day release for eight weeks to gain a more detailed understanding of dementia, followed by assorted other activities such as fund-raising for six months. This is certified training that enables them to cascade their knowledge to others. Quality Care has put together a team with strong leadership skills to provide their in-house training. In-house 'Preparing to teach in the lifelong learning sector' (PTTLS) trainers and learning mentors, together with the management team, have developed a robust training plan for new employees. In addition, the dementia dignity champions are also involved.

Quality Care regularly attends meetings with the local dementia partnership, enabling them to create and develop links with other professionals and services within the borough. This also keeps them up to date with any new support groups forming in the community.

This information, together with available literature, is then passed on to the care team who can then relay it to family carers who may not be aware of dementia-friendly activities available to them in their communities.

The training group plans initial group discussions around dementia, including the different types of the disease, and they have found that this is the most effective way to involve all trainees. These discussions are also good indicators to the trainers of what each individual knows and understands.

Training tools used in the initial training are:

- training DVD – 'Understanding Dementia'
- question and answer sessions
- role play(s)
- group discussion around misconceptions about people with dementia
- online distance learning.

Unless a new worker has encountered dementia via a family member or in a previous field of care, their perception of dementia is quite often negative. The whole idea of the training plan is to provide a positive understanding of dementia which dispels all misconceptions which others with less knowledge in this area may have.

Some of the common misconceptions around dementia include:

- only old people get dementia
- people with dementia are all aggressive and/or violent
- nothing can be done for people with dementia
- people with dementia are a danger to themselves and possibly to those looking after them
- people with dementia cannot think for themselves.

Key areas that the training addresses include:

Dementia as a disease

- People with dementia are able to live well with the right support and that a diagnosis of dementia is not the end of their life.
- Care workers not only provide care for the person with dementia, they also provide support for family carers.
- Dementia cannot be cured but medication may improve its symptoms.
- Confusion does not necessarily mean the person has dementia, as confusion can result from a number of reasons.
- Dementia is not necessarily a natural part of the aging process. Some forms of dementia can be triggered by other illnesses, e.g. stroke.

Additional support from other organisations

- The importance of assistive technology devices and what may be available to a person to reduce any risks in their home, enabling them to live independently for longer.
- New workers are informed of local professional teams and what interventions can be provided to support people with dementia.

Dignity and person-centred care

- The importance of maintaining dignity and respect.
- The importance of effective communication, including eye contact, tone of voice and body language.
- The need for person-centred care.
- People with dementia may remember quite clearly aspects of their formative years. New workers should be encouraged to talk to them about what they used to do for their work, what music they like to listen to, etc., – all this information will be kept in their personal information care plan.
- People with dementia should be encouraged and prompted to do as much for themselves as possible in order to promote independence.

Nutrition and hydration

- Sometimes a person with dementia will forget that they have eaten, or will sometimes think that they have eaten. It is therefore vital that the care workers look for clues as to what they may have eaten or, for that matter, thrown away.
- The importance of always knowing what food stuff is in the fridge and cupboards, and the need to check for out-of-date foods as a person with dementia might not check the dates.
- The importance of encouraging the person with dementia to eat and drink. The new worker should also be aware of the need to leave sufficient drinks as dehydration can result in further confusion.
- Care workers need to read the care plan notes to check what the person with dementia has eaten over the period of a few days in order to avoid repetition of meals.
- Care workers need to understand the protocol of reporting any problems the person experiences during eating. The person with dementia could have swallowing problems or require a particular diet; concerns should be referred to health professionals for further assessment.

Following their initial induction, the new worker is allocated a learning mentor who is available for further discussion and to offer advice. The new worker is encouraged to speak with their mentor daily, initially to provide regular reports on their progress. The frequency is reduced when the new worker becomes more confident and competent.

Introductions between the person being supported and the new worker are made by the learning mentor, and the worker is observed while providing care, and support and feedback is given.

The new worker provides continuous service to that person under the supervision of the learning mentor until all parties feel comfortable that the care is working well and the person's needs are being met.

Monthly group meetings are held for new workers by the training team to discuss any further training needs. In addition, refresher group training is held for all care workers every six months.

Practice example

Through local dementia partnership meetings, Quality Care has developed a bond with a family carer who cares for a parent with dementia. He has had to resign from his job to become a full time carer and he very kindly volunteered to speak with small groups of staff about the difficulties he has encountered. He is able to offer advice on effective methods which he uses to overcome the ever-changing obstacles that caring for someone with dementia brings, and offers suggestions on how family carers can be supported in the process. This part of the training enables staff to see things from a different perspective, and is not only often emotional but also inspiring.

2 Motivation of homecare workers who support people with dementia

Five top tips for managers:

1. Base recruitment on values and competences.
2. Ensure employees have the expertise, support and tools they need.
3. Understand situations from the worker's perspective.
4. Treat homecare workers as professional experts and support their career development.
5. Have clear and achievable goals so that success can be verified and celebrated.

The **Good Care Group** is a high quality provider of live-in care services which enable older people to stay safely and happily in their own homes and communities with round the clock one-to-one support.

Motivation refers to the energy and commitment with which an individual or group performs a task or role. Motivated workers deliver higher quality care because they care about what they are doing. They often learn faster and have more ideas and are less likely to make mistakes. Motivated homecare workers are enthusiastic, patient and encouraging to others. This impacts on the care they deliver to individuals and families (Benson & Dundis 2003).

Retention in the home care sector remains a challenge for employers, with average turnover rates of 32.6% (Unison 2012). Undoubtedly, staff motivation plays a critical role in maintaining workforce stability. So why does motivation remain such a challenge in homecare workers supporting people with dementia? Factors include:

- lone homecare workers
- varied hours
- complex work
- poor integration across health and social care services
- funding
- poor levels of pay.

Care work is one of the most rewarding and self-fulfilling career choices. Homecare workers spend time giving to the most vulnerable people in our communities; they support families to stay together, give older people the choice to remain in their homes and people with disabilities the chance to lead an independent life. Homecare workers go home at the end of the day knowing that they have made a real difference to somebody's life and how they choose to live it.

Intrinsic motivation seems to be the key to a homecare worker's performance and fulfilment. Employers should strive to create an environment where intrinsic motivation can flourish.

The Good Care Group has introduced the following five steps:

1. Recruitment based on values and competence.
2. Ensuring employees have the expertise, support and tools they need.
3. Understanding situations from the worker's perspective. .
4. Treating homecare workers as professional experts and supporting their career development.
5. Having clear and achievable goals so that success can be verified and celebrated.

Recruitment based on values and competence

Care work is not just a job, it's a vocation. Caring for someone with dementia can be challenging, especially as a lone worker. Ensuring the 'right' people for the role are selected is the first step towards developing a motivated workforce. Having a robust recruitment and selection process is critical, according to the Fifteen Factor Questionnaire (www.15fq.com).

- Probe for values: new knowledge and skills can be taught, but homecare workers have to start with the right values.
- Competence-based interviewing: identifying core skills and competences that homecare workers need from day one, using a research-based interviewing framework.
- Use more than one source of evidence: the Good Care Group has developed a process for recruitment which always includes telephone screening, face-to-face interviews, group interviews, psychometric profiling, selection and assessment days, group observation and peer feedback.

Ensuring employees have the expertise, support and tools they need

Homecare workers provide care for the most vulnerable people in our society with little immediate backup or support and they need to feel equipped to carry out their role effectively. The Good Care Group has developed the following support and training mechanisms.

- Robust training in dementia care skills. Skills-based training is vital, supported by formal knowledge of medications management, moving and handling and managing risk and safeguarding.
- Having support 24/7: It is important for homecare workers to know that there is someone out there offering support – someone who has 'walked a mile in their shoes', who can coach them through difficult situations, or just offer a listening ear and a shoulder to cry on when times get hard.
- Clear lines of escalation: definition of roles, responsibilities and professional boundaries is critical in homecare.

Understanding situations from the worker's perspective

In addition to the duty that everyone in social care has of understanding care from the standpoint of the person being supported, it is also vital that an 'us and them' culture is not allowed to develop between homecare workers and management and administration staff. In the Good Care Group's experience this can be achieved by the following.

- Seeking feedback and acting upon it – use of employee surveys, opportunities for group verbal feedback, annual appraisals and supervisions. Ensure any actions you plan to take in response to feedback are clearly communicated and agreed with your team and followed up in a timely manner.
- Fostering a culture where feedback is always received as a gift is vital. Homecare workers may, by their nature, not be very confrontational people. They can keep their worries to themselves until they reach breaking point. Having a policy where feedback can be given and taken constructively will enable homecare workers to air their concerns and opinions.
- Having a robust process for when a worker raises a concern, grievance or resigns: have an objective person talk to them, who can hear what they have to say and make independent recommendations for improvements.

Treating homecare workers as professional experts and supporting their career development

Homecare workers will often become the 'expert' in providing care for a particular person, they build up a wealth of knowledge and skills throughout their careers and can often achieve success with a person with dementia where doctors, nurses, family and other people cannot. They must be respected as the experts they are and treated as true professionals (Low Pay Commission 2012; Unison 2012).

- Ensure employment packages reflect the professional status of the homecare worker's role: flexible working hours, holidays, breaks and a good work-life balance, wages which reflect the work they do.
- If care work is to be professionalised and seen as a true career, then continuing professional development (CPD) is critical. Homecare workers need to know that progression is tailored to their strengths and preferences. Not every worker wants to complete a management course; some may wish to specialise in areas such as dementia, rehabilitation or palliative care. Learning and development should be valued and rewarded by employers who can now offer more highly skilled workers to people being supported.
- Homecare workers often know the individual better than anyone. Empowering homecare workers to be able to liaise with doctors and family members on an equal footing is vital to ensuring a motivated workforce.

Having clear and achievable goals so that success can be verified and celebrated

Dementia care can be complex and appear chaotic (DH 2009, 49). Creating wellbeing and harmony for a person may feel like an insurmountable task. Focusing on achievable goals will help homecare workers to realise the successes they have.

- Care planning meetings should involve the individual, the care worker and the family and should always be centred on what the whole team are collectively trying to achieve. Goals should be SMART – specific, measurable, achievable, realistic and time-oriented.

- Successes should be celebrated and publicly recognised. Compliments should be shared with the wider team, and certificates of recognition awarded by a senior person. Performance reviews should focus on the successes that a care worker has achieved with an individual. Novel approaches and clever tactics to care delivery should be shared as best practice.
- Understand what good looks like: great dementia care is not just about keeping someone alive, it's about helping someone to live well with their disability “without their dementia”. Success will look different for each person.

Summary

Good homeworkers have many qualities to enable people with dementia to live well: courage, tenacity, ingenuity, self-sufficiency, empathy and patience.

Having a recruitment and selection process which enables you to find these people is the first step in creating a motivated workforce. Once someone with the right values has been recruited they need to be motivated and inspired them to develop into homeworkers who are skilled and able to improve the lives of people with dementia.

Treating homeworkers as the professional experts they are is critical. It is the responsibility of the employer and the care worker to support a climate of personal growth and development, to work together to provide round-the-clock expert support and ensuring that training programmes are not just ticking boxes but supporting the development of the skills needed to promote wellbeing for people with dementia. Listening to employees – respecting their opinions and acting on their feedback is vital. So too is ensuring that workers are given a very clear picture of what good looks like.

Practice example

The Good Care Group sees great homeworkers reap the intrinsic rewards of being able to make someone's life better. For example: re-introducing Mrs Smith to her church on a Sunday, finding a way of enabling Mr Jones to trust the worker enough to take his medication again, or helping Ms Brown to die peacefully in the comfort of her own home are all individual goals that a care worker can be supported to achieve to enable a person to live well with dementia (National Dementia Strategy 2009).

Helping homeworkers to achieve these goals and then celebrating success as a team is how to motivate homeworkers. In 2014 the Good Care Group is committing to the Skills for Care-led Social Care Commitment to share the work they do to provide excellent care for people with dementia and their families.

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Benson S & Dundis S 2003 Understanding and motivating health care employees: integrating Maslow's hierarchy of needs, training and technology. *Journal of Nursing Management* 11, 315-320.

Fifteen Factor Questionnaire (15FQ+®) <http://www.15fq.com>

DH 2009 - Department of Health, *Living well with dementia- A National Dementia Strategy* https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

Low Pay Commission 2012 - National Minimum Wage Low Pay Commission Report
Unison 2012, Time to Care: a Unison report into home care
<http://www.unison.org.uk/upload/sharepoint/On%20line%20Catalogue/21049.pdf>

Other useful resources

Contented dementia: www.contenteddementiastrust.org

Department of Health, Improving care for people with dementia - The Prime Minister's Challenge DH (2013)
<https://www.gov.uk/government/policies/improving-care-for-people-with-dementia>

NICE guidelines for dementia 2012 p.15
<http://www.nice.org.uk/nicemedia/live/10998/30318/30318.pdf>

Skills for Care dementia resources
<http://www.skillsforcare.org.uk/Skills/Dementia/Dementia.aspx>

3 The importance of a flexible workforce and continuing professional development

Five top tips for managers:

1. Continuity is as important for workers as it is for people who need care and support.
2. Support and supervision for workers is essential.
3. Ensure company ethos is sympathetic and encouraging for workers' learning requirements.
4. Involve workers in planning their own learning and development.
5. Match workers to the work, taking into account capability and interest.

As a domiciliary support provider, **Ann Tuplin Care Services (ATCS)** in North Lincolnshire is seeing more and more people with complex needs, supporting those with dementia at all stages to remain at home and live as independently as possible.

Training for staff at ATCS covers the usual areas of practical support and delivery of personal care with dignity and respect but also takes in the top tiers of Maslow's 'Hierarchy of Needs' (cf. www.simplypsychology.org/maslow.html) to include socialisation, esteem and self-actualisation for people being supported and their families. Management are also aware that these ideals apply also to workers, and endeavour to provide emotional support and fulfilment for workers at all levels. Training is provided in a way that suits the individual, so group sessions are arranged, distance learning is offered, and one-to-one training and individual mentoring are also available.

Frequent (eight weekly) supervisions are arranged and recorded, where workers can discuss concerns or issues. A learning and development plan is formulated in conjunction with each worker at their probationary interview and is reviewed at each supervision and annual appraisal. Annual appraisals are a time for reflection and forward planning to map out a pathway for the worker to help with their progression.

For a worker to provide the best care whether it is personal care, social care, community or emotional support, they need to have the skills and confidence in themselves. However, they need also to have the confidence in their line managers so that they will feel supported and know that, although they may be asked to step out of their comfort zone, they will not be made to feel uncomfortable or inadequate through lack of knowledge or training.

ATCS's policy is to involve workers in reviewing support packages as they are the people who know what daily tasks and support is required. Very often the worker and person who is being supported will discuss changes together and then take them to the line manager to see if they can be implemented. This appears to work particularly well when social time is being provided and when times need to vary to suit specific planned and spontaneous activities.

Practice example

Lucy had two care workers to provide assistance for personal care calls, four times a day, as she needed to use a hoist; she also had one care worker to provide nine hours of social time per week. Some social time was planned for 10am to 12 midday for Lucy. Jilly, one of the workers who provided her morning personal care call was to stay on for this time and accompany Lucy to do some grocery shopping but, as the workers were assisting Lucy to wash and dress, they discussed the plans for the morning and Lucy said it was a pity the time finished at 12 o'clock as she had heard about a new café she was keen to try but having to be home by 12.00 would not leave them time to relax and enjoy lunch. Jilly contacted ATCS's co-ordinators who agreed that the two lunchtime workers should be cancelled and Jilly could stay with Lucy as long as it took to enjoy lunch and then get home. Adjustments were made to Lucy's social time later in the week to account for the additional time.

ATCS has had some positive outcomes from ensuring that workers are selected for individual packages, matching them as far as possible to the person being supported and their family's preference regarding gender and age. It is essential to get the right worker as support is vital for the whole family unit, not just the person being supported.

Workforce development and learning is an ongoing process and cannot stay static as the people supported by the service have fluctuating conditions and circumstances, so new skills and competences can be required to meet their changing needs. If all workers continually develop their skills they can remain supporting the person without a need to introduce new workers, and thus retain consistency of care.

Practice example

Recently ATCS was asked to put in support for a family where the person who needed care and support had advanced dementia. Mike was receiving support to live at home with his wife, Emily. Mike appeared happy with the previous workers, but Emily did not feel comfortable with them and as a result was near exhaustion because she could not relax when workers were about, especially during night visits, and was not able to sleep.

After discussion with Mike and Emily, ATCS identified a core group of four workers and discussed the package with them. One worker felt she did not have the necessary experience; she felt able to cope with Mike's personal care but was unsure about his and Emily emotional needs, but was keen to become involved. The workers were introduced individually to the couple and Emily was keen for all four to support them. Emily was told that if she felt uncomfortable in any way with a worker all she had to do was tell the manager, she did not even have to give a reason. Within a week Emily felt able to go out for lunch with her daughter and leave Mike at home with the care worker; this was huge step for her as she had not been out without Mike for over a year. When Emily returned home she found Mike and the worker playing some his old favourite records and both were singing along to them. Mike greeted Emily cheerfully and then carried on singing.

When Mike went for a nap a little while later the worker made Emily a cup of tea and answered questions about Mike's mood and behaviour while Emily had been out. During this conversation Emily burst into tears. Although feeling she had done something wrong, the worker gently questioned Emily as to why she was so upset, but Emily replied that she was not upset but relieved.

The worker went to the office and requested an early supervision as she was a little bewildered; this was the worker who had initial reservations. During the supervision the worker discussed that particular incident with her manager and as she talked it through came to the realisation of why Emily was so emotional and began to understand the positive impact of her actions for both Mike and Emily. Initially she said "But all I did was ask Mike if he liked music and he showed me his records so I decided to play them for him. I thought I would get into trouble for singing with him." The manager was able to explain that for a short time both Mike and her were in "the same world" which was a benefit to Mike, without making him feel confused or the worker having to patronise him.

Unfortunately Mike died a few months later, but after a year had passed Emily's daughter contacted ATCS and asked if that particular worker would be able to support Emily to socialise and re-establish her place in the community as she had become quite reclusive and lacking in confidence since Mike's death. The worker was asked if this was something she felt able to do, as this would be purely emotional support and she had initially expressed reservations about this type of support. The worker was more than happy, saying she now felt able to offer emotional support along with practical help and personal care.

4 Supporting workers providing care for people whose behaviour may challenge, in their own homes

Five top tips for managers:

1. Leadership: be clear on your leadership influences and translate these into your business plan. Have a clear vision of what services you want to provide, and include workers, customers and carers in shaping your services.
2. Developing and supporting workers is a sharing process; assist workers to be accountable for communicating difficulties and changing needs.
3. Dig deeper when faced with labels such as “challenging behaviour”; often the person who needs support is trying to communicate.
4. Person-centred care is challenging to get into every day care; attention to detail on support plans and their formulation process is key to working this way.
5. Communication: what do we do with it? Look at the lines of communication open to workers, customers and carers and let them witness the effectiveness of communicating. Highlight changes that have taken place due to their input.

Care Direct Salford has developed an approach to developing and supporting workers to support people with dementia whose behaviour may challenge, in their own homes. Care Direct has provided specialist support to people with dementia since 2005 when a clear direction was established to change the way services were provided to people who had dementia. It was the success of this approach that enabled Care Direct Salford to provide support to people with dementia where other agencies had not been successful due to challenges in behaviour and individuals not engaging. Care Direct Salford's approach proved so successful that it enabled support to be provided also to people with dementia who were in a secure setting due to their challenging behaviour. This support took people out of secure settings and re-engaged them with communities. The main body of this case study reflects how Care Direct Salford enables a skilled workforce to provide support to people with dementia in their own homes.

The purpose of Care Direct Salford when it was formed was to provide specialist support services which maximised a person's potential to function with the appropriate level of support. This support was to enable individuals and their carers to have a say in how they would like their support tailored to their needs.

In journal articles in the 1990s, Kitwood focused on 'personhood' and the importance of preserving this when caring for a person with dementia. Defining personhood as "A standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust" (1997), Kitwood asserted as the foundation of person-centred care that "The task of care is maintenance of personhood and the uniqueness and individuality of all is recognised regardless of diagnosis." . It is how we translate person-centred care into everyday practice that makes the difference in working with people whose behaviour may challenge.

If workers consider behaviours which challenge as attempts to communicate rather than as a person being "challenging", they can often see a reason why a person's behaviour is the way it is, regardless of diagnosis.

The person-centred approach has developed considerably in the understanding of behavioural aspects of dementia and a study by Cohen-Mansfield (2005) provided convincing evidence that so called 'challenging behaviour' is just a person's response to not recognising the individual physical or social needs of people with dementia. It is critical that meaningful activity is part of the individual's care. The focus is on involving the individual and utilising workers as enablers to fill in the gaps. Following this approach ensures that workers develop a greater sense of satisfaction by supporting people to achieve goals rather than 'doing things for' people. This underpins the care and support that the organisation provides.

Initial assessment and information gathering is an essential part in supporting workers when they first start to work with a person whose behaviour may challenge. Person-centred packs are sent out to people in need of support and to the significant people in their lives prior to work beginning, to get families and carers thinking about what is important to the person who will be supported. Supporting and developing thinking around support for both workers and families/carers is critical if person-centred care is to work. This also encourages families and workers to share their experiences of what they have found difficult when caring for the person whose behaviour may challenge and supports them look at what has happened prior to the challenges taking place.

Once the initial process has taken place it is good practice to introduce workers to the people with whom they will be working. This helps break down any fears a worker has, especially if it has been highlighted that specific support could potentially be challenging to both the worker and the person they are supporting. Taking a photograph of the worker at the person's home to put in the file (with consent) starts building relationships and trust.

Part of the worker's development is contributing to live documents which they have to present in supervision. Workers take the lead on recording what is working and what is not. Workers write support plans using words which are important to the person they are supporting. Ensuring workers have knowledge around different types of dementia and how this affects people, including dual diagnosis dementia, is also important. Common themes for each type of dementia can be used as a basic knowledge to understanding some aspects of behaviour. Team meetings are used to discuss approaches that work with people whose behaviour may

challenge. Workers also understand that what might work one day may not work the next, and this challenges their expectations. This approach can develop workers' confidence and encourage them to be vigilant to changes in needs of the person they are supporting.

The agency encourages workers to use activities as part of the person's support, especially if the need is a specific care need. This includes the use of music, photographs, and other memories in everyday support. The workers are supported to get involved in life books and utilise all their knowledge they have of that person to provide a calm, supportive, interesting and productive time. Such close involvement with the person being supported makes any changes in that person's health easily identifiable. Part of the worker's role is to record such changes and communicate them to their manager. Workers are continually helping each other to develop their own understanding of the individuals they are supporting and of challenges that are happening within them.

Documents which help workers provide support to a person whose behaviour may challenge include detailed risk assessments, person profiles, support plans and incident logging.

- Detailed risk assessments are imperative to the safety of workers, particularly if a person has displayed behaviour which has challenged people before safeguards are put in place. These safeguards could include what to do if the person refuses medication or displays verbally aggressive behaviour which may challenge workers. The document shows that potential situations have been considered and the likelihood and frequency of these arising has also been assessed. The workers are supported by having clear guidance as to how to react in these situations, as often when faced with adversity it is human nature to react in different ways. The thinking behind providing workers with this document is to support them to have a consistent approach and to communicate that consistent approach to the person they are supporting.
- Person profiles are completed with the person being supported. This document focuses on likes and dislikes and identifies what is important to supporting the person at that specific time. Information might include, for example, "I do not like people to talk a lot" or "I like a cup of tea before taking my tablets."
- Support plans are person-centred, so any information regarding the specific care need is written from the person's perspective and states how they would like that specific support to be delivered.
- Incident logging is used for identifying trends, e.g. "On Monday morning Mary was shouting, this stopped 10 minutes into the visit after Mary had a cup of tea." This tool assists Care Direct's managers and workers to identify if there are any recurrent factors in reported incidents, e.g. it being Monday after the weekend, a particular worker or time of day, etc.

Effective communication is a foundation stone to how Care Direct Salford operates. Their purpose, vision and values all include participation not only from leaders but from workers, customers and people they support.

Care Direct Salford supports workers in a way that is inclusive, with a support and development structure that aids them to support people whose behaviour may challenge in a way that is enabling by providing safe, holistic, reliable, responsive and professional services.

Resources

- Kitwood T, 1997 Dementia reconsidered: The person comes first. (Buckingham U.K, Open University Press) <http://www.amazon.co.uk/Dementia-Reconsidered-Person-Rethinking-Ageing/dp/0335198554>
- Brooker D, 2006 Person-centred Dementia Care. Making services better. (Jessica Kingsley Publishers) <http://www.jkp.com/catalogue/book/9781843103370>
- Loveday B, 2012 Leadership for Person-centred Dementia Care. (Jessica Kingsley Publishers) <http://www.jkp.com/catalogue/book/9781849052290>

5 Enhancing quality of life through activity-based support

Five top tips for managers:

1. Always have a dementia link worker at meetings, to ensure due consideration is given to this important area of care.
2. Ask a support worker to find something new each week about a person with dementia and report back to the team. This encourages more varied conversation and activities with individuals.
3. Know what is going on in your area and who the key people to contact are, for example who are the dementia advisers? Who is the village agent? These people will help keep you up-to-date with activities and events which might be beneficial to individuals with dementia.
4. Empower your dementia link workers to liaise with social workers and families; families in particular will have a wealth of knowledge about their loved one which can be the basis of activities, conversation and meaningful moments.
5. Use the Kitwood equation to problem solve: life history is very important but this needs to be combined with knowledge about an individual's health conditions, their social psychology and personality. Together this will give a true understanding of the person's needs and help with a person-centred approach.

DoCare is a homecare provider based in Gloucestershire and covers various areas in the South West of England. DoCare places great emphasis on the importance of dementia training. A structure is in place which ensures information, learning and best practice is circulated to the team and they adopt a robust approach to dementia care. The structure comprises a dementia lead with a second tier of dementia link workers, and a third tier of a body of support workers, all of whom have training in dementia. In this way, they ensure a seamless, joined up approach to the support of the individual.

DoCare is currently creating a handbook for all its workers. This will put into print all the dementia learning the organisation has, so it will act as part-manual, part-reference guide; it will be particularly useful for new workers, by supporting their dementia training, but will be an invaluable resource also for all the workers.

Central to the support DoCare delivers is emphasis on activities which will stimulate people with dementia, and which add value to visits by making them much more than functional and practical. The handbook will also help workers by offering different ideas on how to support activities, from things that can be done in a short visit to activities suited to longer visits. Support workers are also empowered to be spontaneous and to 'think outside the box'. Having a handbook is only part of the approach. Workers are encouraged to be reactive to situations, and be alert for clues in a person's behaviour which will lead to spontaneous activity and meaningful moments. Underpinning everything is a commitment to treating each person as an individual, adopting a person-centred focus, and finding out particular areas of interest, so activity-based methods are bespoke to that individual.

Increasingly the organisation is being asked to deliver sitting services for individuals, while at the same time the emphasis is moving away from short, 15-minute visits. This has meant that a more robust approach to visits has been needed, so the longer visits in particular are more meaningful for people with dementia.

In the first instance, for all people, whether or not they have dementia, an 'I Am' booklet of preferences is completed, which details as much information about the individual as possible including likes and dislikes, hobbies and interests. Building on this, support workers are expected to be very observant, noticing the small things about the individual or about their environment.

Using all this information, activities can then be devised. Some activities will be ad hoc, others more prescribed. They can involve either doing something with a person, or a conversation-based activity, or perhaps compiling a memory album which each team member can refer to and make use of during a visit.

At the same time, workers are thinking on their feet and reacting to situations so they can create spontaneous, meaningful moments for individuals. The following are some examples of how DoCare workers have taken the knowledge they have built up of an individual and used it to create a meaningful activity. Indeed, in two cases – those of Peter and of Henry – DoCare workers can demonstrate that the understanding they have of the person has helped support them in the face of proposed changes to care by social services. All names have been changed.

Practice example: helping an individual to keep up a hobby

Peter suffers from vascular dementia following a stroke; he finds it hard to communicate and has a limited vocabulary.

When DoCare took over Peter's care package, it included a weekly trip to a local fishing lake; a support worker took him, stayed with him while he fished and took him home afterwards. This activity helped to give him a change of scene, an interest and – above all – was a memory jogger, bringing back sounds and sights that were familiar.

Peter was upset when social services decided to remove this part of his package. The support team for Peter – which was kept to as few people as possible, so they were able to build a rapport – could understand how upset he was. He would talk (and swear!) about fishing, and how he wanted to go fishing.

DoCare intervened on Peter's behalf at a review meeting, and were able to help reach a compromise that enabled him to carry on with his interest. Peter finds communication difficult, but by asking questions with yes/no answers, rather than open questions, he was able to demonstrate how important this fishing activity was. For example, "Do you like fishing?" and "Would you like to go fishing?" would prompt a "Yes"; more complicated questions, such as "What sparked your interest in fishing?" would be difficult for Peter to answer.

Social services agreed to reinstate the trips, if a DoCare support worker took him to the lake and collected him later. Peter's condition means he is perfectly safe to be alone at the fishing lake.

Before his stroke, Peter, who is only in his sixties, had an active life. The intervention of DoCare has meant that he can continue to take part in his favourite activity, it is something he looks forward to and it gives him a focus. The fishing also helps Peter maintain his fine motor skills, and improves his general wellbeing by giving him fresh air and exercise. It keeps him independent and in touch with the fishing community he has become a part of, and this socialisation will help him to remain independent for longer.

Practice example: how a shared interest provides meaningful moments

Henry suffers from dementia and finds it hard and frustrating to get his thoughts and feelings across, often limiting his conversation to what happened in the past. A former professional footballer and committed family man, his conversation centres around soccer and happier days with his wife and son.

The example of Henry shows how important it is to have the right worker matched to the individual. Knowing how much he loves his football, DoCare ensures his most regular worker is Simon, who is equally football-mad! Simon spends time with Henry talking about football and watching it with him on the television. This sparks conversation with Henry about football both past and present.

Recently, the DoCare team were able to support Henry in his desire to remain at home when he was faced with the prospect of having to move into a care home. Now allowed to remain at home, Henry can carry on watching football on television and chatting about his passion with Simon.

Practice example: taking people on trips out

Kathleen is in her fifties and has early onset dementia. She finds it difficult to communicate verbally and also has problems with her balance, which means that, although she is not in a wheelchair, she cannot go out without support.

DoCare support workers spend time with Kathleen taking her out into the community. They try to make the experience different each time; for example, Kathleen is a keen artist but is no longer able to participate in this activity herself, so a visit to a local art show had great value for her and boosted her general wellbeing and morale.

Overall, the trips out have greatly improved Kathleen's confidence. She looks forward to each visit which is tailored for her needs and helps her to keep in touch with, and feel part of, her community. These excursions also help with her physical wellbeing, as they provide her with exercise and a change of environment. Fortunately the visits with her are long enough to be able to do this.

Practice example: focusing on a person's interest

DoCare also believes equally good value can be given even during a 15-minute visit, which they make as part of an overall package of care.

Barbara had always been hard to engage with, and keeping up a conversation was very difficult. Workers noticed she had many small dragon ornaments around her house, so started a conversation around them. Barbara was quickly engaged, and spoke about how much she had enjoyed collecting them over the years. Now the DoCare team always chat about them; it's an activity which lasts only a few minutes but it has her engaged and makes her smile.

Practice example: utilising a person's skills

Care is not only delivered by relying on a prescribed formula. Being spontaneous with a person is just as important, and often it is important to look at an individual's own skills as a cue to providing an activity.

For example, an area manager was recently with a person with dementia. All tasks had been done and the conversation was beginning to run a little dry. The area manager knew Freda enjoyed crochet. The area manager told Freda she could crochet circles but didn't know how to crochet corners and would Freda show her? They spent a happy time together with Freda demonstrating cornering and chatting about crocheting.

This spontaneous activity arose from the area manager's knowledge of Freda's interests and provided a wonderful meaningful moment for Freda.

DoCare has learnt that dementia care is enhanced by introducing activities for people. These activities need not be excursions, or take a long time. They can be adapted to suit short visits or long. For example, a short visit can be enhanced by a chat about an object in a person's home (like Barbara's dragons), sharing a news story, or a walk around the garden. Potting up a plant, playing a game, or companionably watching television all provide an activity-based focus for a person. For longer visits, baking a cake, visiting a coffee shop or going to a community event can give stimulation and enjoyment.

Equally important is to be reactive to circumstances; for workers to provide spontaneity and to avoid activities being too rigid and prescribed. Here, looking at a person's own skills can be key—a person can pass on their skill to workers, whether that's teaching them crochet or

explaining the offside rule!

While it's true that many more people will suffer from dementia, it's also true that early diagnosis and activity-based support can help alleviate the symptoms and enhance quality of life and independence.

Useful resources

- The Alzheimer's Society - www.alzheimers.org.uk

6 Co-production between the social care workforce and carers

Five top tips for managers:

1. Anxiety is an entirely natural feeling when supporting people with dementia for the first time.
2. Focus on techniques to support workers in the situations they may encounter.
3. Allow opportunities to practise with appropriate support.
4. Involve and support family carers where you can.
5. The use of case studies where things have gone well supports learning and development.

Specialising in non-medical care of older people in their own homes, **Home Instead Senior Care** assists people to remain at home where they're most happy and comfortable, giving their families the freedom to relax in the knowledge that their loved ones are in excellent hands. Its homecare workers are called CAREGivers.

“How did you feel the first time you met a person with dementia?” is the opening line of Home Instead Senior Care’s Alzheimer’s and Other Dementias Train the Trainer Course for CAREGivers (staff). The answer is nearly always the same, “Frightened”.

Further questions include “What is your experience of how family members feel?” and “What do you think that make the person with dementia feel?” It is the same answer.

When this is considered in greater detail, the reasons why workers feel ‘frightened’ is because they are unclear how to support people. Home Instead’s approach with the course is to change all that for the benefit of workers and most importantly for the benefit of the people with dementia whom they are supporting.

Home Instead’s training course empowers its CAREGivers with the knowledge to confidently manage and improve typical situations encountered when supporting people with dementia.

The course, developed by experts in the condition, avoids the “medical model” of training based around disease management and, instead, focuses almost exclusively on techniques and skills to enable the CAREGiver and the individual to interact positively and constructively.

Home Instead delivers the training to their CAREGivers over a six week period. CAREGivers receive intensive classroom training in several sessions coupled with opportunities to practise their new skills between sessions. To maintain the interest and commitment of the CAREGivers over such an extended period needs everything to work effectively.

Fundamental to this is the performance of the trainer themselves. They have to be able to deliver not only the course content, but also to demonstrate a real passion for the subject. Facts can be quickly forgotten, but we don't as easily forget how we felt about something, so to listen to a trainer who can describe the emotions faced in caring for someone with dementia is just as important as the lessons learnt.

To be able to do this the trainer needs more than just to be well prepared. They need more than just the facts at their fingertips. They need to be able to make the learners feel that this matters on a personal level.

To make this happen Home Instead runs a residential "Train the trainer course" at its national headquarters in Warrington.

Prior to attending, each delegate is sent a comprehensive pre-read including a book entitled *Confidence to Care*. This forms the basis of an important element of the actual course. The book contains personal stories of how the tips and techniques in the training materials have helped to improve situations among those providing care and those who have a dementia.

A national qualification awarding body has accredited the CAREGiver programme, which underpins its quality. The desired outcome is a group of motivated and qualified trainers who feel confident to inspire others. So far almost 200 of Home Instead network's trainers have attended the courses and over 1,000 CAREGivers have received their certification.

Through a series of "family carer workshops", Home Instead also now empowers families and the wider community to understand and interact with their loved ones. The family carer training is based on the classroom lessons for CAREGivers, but at a stripped-back level. The key aim is to educate anyone who interacts regularly with someone who has dementia on how to cope and, particularly, how to change from being frightened of the condition to feeling confident that they can have a positive impact on the situation.

These workshops are offered free of charge and already tens of thousands of people across the country have been trained. And it isn't just families who have been given access to these new skills. Retailers, hairdressers, fire service, police, pharmacies, charity volunteers and many more are among those who have benefitted from the workshops. One of the focuses of the Prime Minister's Dementia Challenge is the creation of 'dementia friendly communities' (see www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf). Home Instead is already a long way to making a real difference and is championing progress at grassroots.

Without appropriately trained and engaged caregivers, a person's life can often be unendurable. Many rely on the support of family carers but when the demands become too high, relationships can become strained. There is no respite. Life in a full time residential home increasingly becomes the only option but with well-trained confident support, none of these things need happen.

Home Instead believes that through better training, a model of care built around a quality care experience, continuity that fosters a lasting relationship with the individual and a culture of learning and development, the face of caring can be changed. It can also be made an appealing career path.

Having a positive attitude is vital in delivering quality care. Workers in the sector must believe in the importance of high quality care. The talents and skills of workers have to be recognised and that these are essential to the quality of life of people with dementia. Being a lifeline for people who want to remain at home can never be undervalued.

Thousands of CAREGivers are delivering on Home Instead's stated aim "To become the UK's most admired care company through changing the face of ageing" and, with better practices and training, the company is helping also to change the face of caring.

7 Using assistive technology to increase the uptake of personal budgets and self-directed support for people with dementia

Five top tips for managers:

1. Promote continuity of care
2. Promote independence
3. Promote autonomy over care
4. Encourage take-up of personal budgets for people with dementia
5. Support carers of people with dementia.

HomeCareDirect is a domiciliary care organisation based in Derbyshire that employs personal assistants on behalf of the people they are supporting. It is a national provider of support services to people on personal budgets and direct payments, and to self-funders. It looks for innovative solutions to minimise the difficulties which people with dementia can face.

Personal budgets and direct payments can bring real benefits for people with dementia. Alzheimer Scotland's report *Let's get personal – personalisation and dementia* (www.alzscot.org) identified the benefits for people and carers as:

- Flexibility, choice, control and consistency over when support is provided and by whom.
- Providing appropriate responses to the particular needs of people with dementia, such as enabling care aimed at maintaining skills and allowing people who are known to the person with dementia to be employed as personal assistants.
- Helping to keep the person with dementia at home in the advanced stages of the illness.

So why has there been such low uptake? The Alzheimer's Society identified a number of barriers to uptake of personal budgets. They recognised systems which:

- are currently overly complex and intimidating for people with dementia and their carers
- had not yet adapted to the needs of people with dementia and their carers, and are overly complex and burdensome
- lacked appropriate support to enable people with dementia and carers to use direct payments.

These conclusions were published by The Alzheimers Society in the report *Getting personal? Making personal budgets work for people with dementia*, where they called for the personal budget system to be adapted to meet the specific needs of people with dementia. A survey included in the report took the views of people with dementia and carers who had been offered a direct payment but were not using one. The survey asked why they had declined and found that:

- 31% said it was hard enough to cope as it is
- 14% did not feel confident managing direct payments
- 11% thought direct payments were too complicated/difficult.

If uptake of personal budgets is to be increased, the barriers which directly affect people with dementia need to be addressed so that these people can also benefit from the advantages of having a personal budget.

HomeCareDirect utilises assistive technology to break down these barriers and promotes wider uptake of personal budgets and direct payments.

The term ‘assistive technology’ refers to “any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed” (Royal Commission on Long Term Care, 1999).

For HomeCareDirect the main outcome associated with personal budgets and direct payments is being able to choose and manage your own care team. Allowing people who are known to the person with dementia to be employed as personal assistants is one of HomeCareDirect’s key principles. A person-centred plan, carefully worked through with the person with dementia and their family, enables the person’s own targets to be reached. These might include anything from daily walks to ensuring that there is an even level of lighting through their home to reduce disorientation. The continuity of care also means that the personal assistants can identify worsening symptoms and help to manage them with the individual and their family at the earliest opportunity.

Individuals with dementia, or their family members, can choose to have a direct payment and take on the legal employer responsibilities for the personal assistants (PAs). However, this can be a daunting task for many. HomeCareDirect addressed this issue by designing a service which actually employs the PAs for people with personal budgets. HomeCareDirect takes on the legal responsibility of being the employer—what is commonly referred to as a ‘third party’ role.

It is the function of a third party organisation to ensure that all the freedom of choice and control is maintained for people with dementia while shielding them and their family from the burden and legal worries of being an employer.

To achieve this there needs to be a variety of support mechanisms in place. HomeCareDirect uses a blend of professional support and assistive technology to set up the ideal situation for people with dementia. In particular, they have overcome two key barriers by developing such technology.

Using the HomeCareDirect iCareBuddy app

When people choose to manage their own care team and are the legal employer themselves, they are responsible for organising the rotas and keeping the timesheets of all the visits their personal assistants make so they can be paid appropriately. This is a difficult paper exercise for many people with dementia. To address this, HomeCareDirect created the 'iCareBuddy' app which is installed onto a tablet device which sits in the person's home and helps individuals and families manage their PAs' visits. PAs are listed on the iCareBuddy and clock in and out through their unique PIN when they start and end a shift. The iCareBuddy then creates an electronic timesheet for each PA, which is sent to HomeCareDirect and used to calculate pay while providing an automated and consistent record of support hours provided.

This removes the need for any involvement from the individual or the family in the creation and maintenance of timesheets and in the payment of the care workers. HomeCareDirect chose to use the tablet PC as the base for the iCareBuddy app due to its unobtrusive nature and the fact that it blends into a person's home.

Online tool to create or amend the rotas

The second barrier to uptake of personal budgets and direct payments identified by HomeCareDirect was the need to create and maintain an appropriate and safe PAs rota, which the individual and/or family had involvement in creating.

To remove this barrier, HomeCareDirect created an online tool that the individual or their family can use to view or amend their care rota, 24 hours a day. This is provided via a secure login on the HomeCareDirect website. The rota can be accessed from anywhere with a computer and an internet connection. When used in conjunction with the HomeCareDirect iCareBuddy, family or friends provided with a login can check from anywhere in the world when visits are due for the week ahead, when visits started or ended, and can view historical care visits, so they can see who has worked and for how long.

Coupled with this, the online rota automatically notifies the HomeCareDirect on-call service if one of the PAs fails to arrive for a visit or is late for a scheduled visit, providing peace of mind for all involved.

These two pieces of assistive technology give the individual and their family the tools and confidence to achieve continuity and autonomy over their care and promote their independence, in line with the recommendations from the Alzheimer's Society.

Even though HomeCareDirect chose to design and implement their own in-house solution, there are numerous cost effective assistive technologies available which can help service providers achieve similar goals. An extensive resource for this can be found at <http://www.atdementia.org.uk> - a website dedicated to providing information on assistive technology for people with dementia.

This case study has shown how one company has used innovative approaches mixed with assistive technology to increase the uptake of personal budgets, direct payments and self-directed support for people with dementia.

The range of assistive technologies is wide, and so is the range of outcomes that can be achieved through their implementation. New technologies are continually being released so it is important to keep an eye on the market to know what is available and whether they could improve services.

All companies should be looking to embrace assistive technology, as HomeCareDirect has shown, in order support people with dementia who may find it difficult to access personal budgets in the traditional sense. We should all work together to ensure that people with dementia and their families are able to access the same control, independence and safety which a personalised approach can deliver.

Useful resources for the use of assistive technology for people with dementia

www.atdementia.org.uk

www.carers.org/help-directory/alzheimers-and-dementia

www.dementiafriends.org.uk

www.alzheimers.org.uk

Alzheimer's Society report: 'Getting personal? Making personal budgets work for people with dementia' available to download at: www.alzheimers.org.uk/site/scripts/download.php?fileID=1281

Alzheimer Scotland report: 'Let's get personal – personalisation and dementia' available to download at: www.alzscot.org/campaigning/policy_reports/2096_lets_get_personal_-_personalisation_and_dementia

8 Supporting workers to deliver end of life care to people with dementia in their own homes

Five top tips for managers:

1. Build a strong, qualified team to support people at the end of life.
2. Train all your workers to be “carer aware” – carers may need as much support as the person diagnosed.
3. Plan as early as possible; leaving it till later means you may not know the wishes of the person.
4. Research and use the excellent resources and training materials available.
5. Work closely with the other partners in the person’s care - see “A Triangle of Care”.

The Department of Health End-of-Life Policy 2008 stated; “...over 60% of people would choose to die at home.” To meet this need in the community, the End-of-Life Team at Cherish Care...for you and your home Ltd developed their learning and skills to provide a positive end-of-life experience that supports the physical, emotional and spiritual progression through the dying process. The Team have a responsibility to support the needs, not only of the person dying with a dementia, but also the family and friends who are close to the individual. Through the use of a case study, this chapter identifies the elements that support a person with dementia to have a good death at home.

A Case Study of George and his family

George, 89, lived at home with his wife and daughter. He was diagnosed with Parkinson’s and then Dementia with Lewy Bodies. When Cherish Care started to visit him ten months prior to his death he had the capacity to make some day-to-day decisions. The End-of-Life Lead spoke with George about Living-Well and planning for his future. Cherish Care had supported Sue to achieve QCF End-of-Life and Dementia Level 3s, and she also attended “Conversations for Life™” training.

Cherish Care has implemented a “Living Well at End-of-Life with Dementia” approach to ensure the person is at the centre of care at all times. The lead initially left the booklet “Planning for your Future Care: a Guide” with George and his family to read prior to arranging a visit to discuss their thoughts on its contents. The lead met with George on his own and they talked through what a Good Day and a Bad Day might look like for George, what was important to him and how he wanted to be supported. She also spoke with his family to see what people liked and admired about George.

George had been a lay-preacher in the Methodist Church as well as serving in the Royal Air Force. His garden was his pride and joy and when he was asked what was the most important thing to him he said, “Keeping my garden beautiful - God’s garden”. He enjoyed getting out in the earlier stages and attended a local self-help group with his wife once every week. When he was unable to do this, the lead arranged with members of the group to visit him at home to keep the outside contact for him.

As part of the personalisation process George was asked what would be important to him on a daily basis as well as for the future, who he wanted involved and also who would make final decisions at any stage. This information was captured on a profile so that everyone who supported him could respect his wishes. It also linked to his Lasting Power of Attorney that had been completed when he was initially diagnosed. Information was also captured on how communication happened between George, his family and other partners when supporting him. George was encouraged to discuss his thoughts and plans about his end of life and how he would like to be remembered. He was also encouraged George to complete an Advanced Care Plan, which was shared and signed by his GP. This ACP helped health and social care workers, as well as the family, to support George’s wishes.

George and Cherish Care workers built up a strong relationship so that when he started to lose his capability, capacity and speech, workers were able to follow his plan and take care of the things that were very important to him. Cherish call this “Little Things Mean a Lot”. As a lay-preacher, prayers and the Bible were important to George and every night workers would read parts of the Bible to him and say prayers. He was still able to say the odd word and, if you missed a word out of the Lord’s Prayer, he would soon let you know. As his garden was important to him, his bed was placed by the window so he could watch the gardener keeping his garden beautiful.

Cherish Care developed an End-of-Life in Dementia Team in order to provide a rapid and professional response when people wanted to stay at home or come home to die. The Team consisted of the Lead and three other seniors qualified to QCF Level 3 End-of-Life and Dementia and two workers at Level 2. This ensured there would always be someone who could lead on different shifts and help other workers support George’s wishes and any changes that happened to his Plan. A key part of workers’ training is that they are “Carer Aware” and the reports shown in the resources have influenced Cherish Care’s training programme.

As George declined he was offered admission to a Nursing Home but in his Plan he had requested to stay at home with no medical interventions. He later became quite confused and refused food and drink so final care started to take place. The family knew that his wishes were Not-to-Resuscitate and he died peacefully at home and the last words he heard were from his wife. Without the Advanced Care Planning and the Living Well approach George could easily have had a less dignified death in a place he didn’t want to be.

As part of their training and development, Cherish Care workers offered to prepare George for the next stage in his journey and his wife was able to see him at peace prior to the Funeral Directors arriving. The Lead was able to sit with the family who were able to see that George had achieved the death he had planned for whilst he still had the capacity. This helped make the grieving easier for them and gave them comfort allowing them to follow George’s Plan for his funeral. The team attended his funeral and the lead also offered to visit George’s family a few weeks later to see how everyone was and to share some happy memories of George. The

lead who is also a trained coach, also met with workers to give them opportunities to cope with George's death.

The planning to develop the team to their current standard started four years earlier when they identified in Business Plans the need to have qualified Leads in End-of-Life and Leads in Dementia with the ability to cross over to both areas. Developing the skills, knowledge, attitudes and habits of the team meant they felt confident in supporting families at End-of-Life, especially where people had been diagnosed with a dementia. Planning for the Team's development meant the same principles, through personalisation, could be applied to the person in need of care and support.

Time spent resourcing available, up to date reports, guidance and materials helped Cherish Care to update its policies, systems and procedures to enable person-centred well-being for all the people they are supporting. The impact this had at End-of-Life was huge for all concerned and helped to improve communication with all parties. It also raised the profile of Cherish Care with other partners showing that they could help people with Advanced Care Plans that could then be supported by all other agencies involved in the person's care and support.

One of the other key areas it raised was how family carers are involved as a partner; recognising their knowledge and understanding of the person and supporting them through their journey. Following up on support for workers and families is crucial for everyone's well-being.

Key Learning Points for Organisations:

- planning for workers' development
- personalisation
- appropriate systems
- involving others
- using resources
- caring for carers and workers

Useful Resources – Templates for assessing, training and planning

"Advanced Care Plan" – guide for Health & Social Care staff – www.ncpc.org.uk

"Planning for Your Future Care: a Guide" - www.dyingmatters.org (contains many other useful resources)

"Difficult Conversations for Dementia" booklet - www.ncpc.org.uk

The Conversations for Life™ Programme - www.conversationsforlife.co.uk - a training programme which offers tools and inspiration to start talking about End-of-Life care

"A Practical Guide to Delivering Personalisation" - Person-centred Practice in Health and Social Care by Helen Sanderson and Jaimee Lewis from Jessica Kingsley Publishers - www.jkp.com

"The Triangle of Care, Carers Included: A Guide to Best Practice for Dementia Care" - www.rcn.org.uk. - includes an excellent assessment tool for organisations

"A Road Less Rocky" - Supporting Carers of People with Dementia - a report by the Carers Trust - www.carers.org

9 Supporting workforce integration across health and social care - Preventing hospital admissions

Five top tips for managers:

1. Train workers well
2. Work in harmony with health and social services.
3. Agreed aims and objectives are important
4. Consistency of care workers is essential
5. Develop a flexible workforce

Meritum Independent Living is a domiciliary care provider based in Kent which offers support and assistance to elderly people, disabled people and people with mental health needs. It is a family run business with long experience in working with health and social care partners to provide excellent services to people with dementia. Meritum care workers provide services ranging from an hour's respite for family carers through to 24 hour live in support. Meritum's sole aim is to promote the independence and wellbeing of those who use its services, supporting individuals and their carers to manage dementia and enable people to remain in their own homes.

In August 2010 Meritum Independent Living (alongside two other social care service providers) was commissioned by West Kent Clinical Commissioning Group, working with Kent County Council procurement services, to provide a Dementia Crisis Support Service.

The aims of the service were

- To prevent unnecessary admissions to hospital or care homes by providing intensive specialist support at home
- To enable people with dementia, or their carers, to recover from an acute episode or crisis situation.

Since its introduction in 2010 there have been many very successful outcomes for those accessing the service and their carers and considerable financial savings due to preventions of admissions. Evaluations of the period 2010 – 2012 showed 69 Hospital Admissions were prevented and 92 care home places avoided. Figures for 2012 to date are still being analysed but show similar positive outcomes. Currently in 2014 approximately £80,000 has been spent with Meritum Independent Living with a saving due to prevented admissions of approximately £600,000.

Training and support for care workers is very important given the challenging situations that the Dementia Crisis Support Service encounters. All social care workers employed on this service have completed the QCF level 2 or 3 Dementia Pathway. This ensures that care workers have a good grounding in the knowledge and skills essential to promote high quality care to people with dementia, and this is extended with Meritum's own in-house training scheme. The training course includes

What is dementia -

- building on current understanding and sharing experiences
 - Understanding what is meant by 'crisis'
 - The pressures on carers and families dealing with memory loss
 - The impact environment has on behaviour
 - The principles of enablement and occupational therapy
- ensuring that they are working to support others who may be involved in care and support, providing integrated services
 - Dealing with dementia crises
 - Assessment and reassessment of the crisis situation
 - Recognising and supporting resolution of the crisis

The nature of this service requires care workers to respond quickly and sensitively to situations which can change very rapidly and be very flexible. The aim is to develop assessment over a period of time, achieving the best outcome for the person being supported. They have developed training and ongoing support to care workers by a range of methods including one to one discussions encouraging reflection on what has been learned, and group sessions where real case studies are analysed.

Case Study Mrs K

Mrs K was referred as her husband, who was her main carer, had injured his foot and was admitted to hospital. Mrs K was diagnosed with dementia and was unable to complete some tasks including meeting her nutritional and medication needs which would usually be supported by her husband. Meritum's workers had successfully supported Mrs K and she was happy with the service and the opportunity to stay in her own home, an environment she felt comfortable with and knew very well. She had continuity of care workers whom she liked, recognised and felt comfortable with. Mrs K now manages on a reduced package of care to just two calls a day on a costed care package of morning and evening calls.

Due to his condition Mrs K husband was admitted into a nursing home however the service still managed to support Mrs K at home and she now spends most of the day at the Nursing Home with her husband and returns home early evening.

The valuable intervention delivered by Meritum's Dementia Crisis Service prevented an acute hospital admission with her husband and in the long term, a permanent placement.

Key reflective learning from this included being able to assess and manage Mrs K's immediate needs and modifying her environment in the absence of her husband. Care workers in Mrs K's home have access to the workers and managers to seek advice.

Case Study Mrs P

Mr and Mrs P are in their late eighties and live in a two bedroomed bungalow on a busy main road. Mr P is well apart from aches and pains; Mrs P is also physically well but suffers from memory loss and has to be guided by her husband. At 2am one Saturday Mr P was disturbed by his wife waking up and going into the kitchen. She then opened the front door and wandered into the main road and sat down. He was very concerned and rang the local ambulance. As an existing customer, he also called Meritum on the 24-hour call out number to ask for help. The on-call workers at Meritum contacted Mrs P's regular care worker, Mary, and explained the problem. Mary is also one of the Dementia Crisis Team and immediately set off to see if she could help. Mary arrived just before the ambulance and managed to reassure Mrs P and encourage her to go back into the house for a hot cup of tea, something she established that Mrs P had wanted to do but had become muddled and wandered out of the door onto the road.

The ambulance arrived and after examining Mrs P decided the best place for her was to remain at home. Mary agreed to stay the rest of the night and call the GP in the morning to examine Mrs P. Mrs P was found to have a urinary tract infection and the associated temperature was causing her to become confused. Mrs P was looked after by a live in Meritum care worker and continually assessed over the next 36 hours whilst her antibiotics took effect and she began to improve. The following week Mrs P was very well and life continued as normal.

Although this case study illustrates a relatively simple intervention, if the Dementia Crisis Service hadn't been available then Mrs P would have taken to the nearest casualty at a very busy time of night. She might have had to wait for a long time and then be admitted to a ward. Because her memory had worsened due to her UTI and the very strange environment she was staying in her discharge would have been difficult and she may have been admitted to a care home. This is a very common route to long term residential care. Because the Meritum Dementia Team was called early it was possible to prevent this. The costs saved in this situation were admission by ambulance to casualty, hospital admission and potentially admission to a care home, and achieved a much better outcome for Mrs P.

Discussions around case studies, identifying what went well and what they can learn for similar situations in the future is a key part of ongoing development for the Dementia Crisis Team. As the service has developed, the growing experience of care workers has been key to learning as this area is relatively new and they need to create resources.

In the future, Meritum would like to be at the forefront in their service area for developing a flexible workforce with a range of skills in ongoing assessment and support, drawing on a range of skills and experiences across the whole team. To secure better outcomes they are looking at how better and more frequent assessment might be used to move from 'crisis management' to 'managing the crisis', earlier preventions and the identification of risk factors. Although there is great value in learning from experiences and practices, and providing the space and time to share this in the team, the considerable savings from this approach could

in part be ploughed back into consolidating the lessons learned into more support for training and development, and investing in earlier assessment of factors that lead to a crisis.

There has been a realisation that they have admitted older people with memory loss too quickly to hospital, the main reasons being carer breakdown or some kind of infection. This can exacerbate the memory problem and make discharge more difficult, resulting in long stays in hospital once the original issue has been resolved. This is very expensive and produces a poor outcome for the person needing care and support.

From the initial in-house training and use of case studies they try to ensure that they identify practice to share, improvements to processes and ultimately, better and more cost effective outcomes for people who use the service. This is important in building the confidence of health and social services to keep people out of hospital and trust in the care that can be provided in the home.

Useful resources that you would wish to highlight to other employers and managers

The King's Fund (2010) Avoiding hospital admissions; what does the evidence say <http://www.kingsfund.org.uk/sites/files/kf/Avoiding-Hospital-Admissions-Sarah-Purdy-December2010.pdf>

Purdy, S and Hunter, A (2013) Predicting and preventing avoidable admissions to hospital: a review Journal of Royal College of Physicians
<http://www.rcpe.ac.uk/sites/default/files/purdy.pdf>

Skills for Care and Skills for Health (2011) Common Core Principles for Supporting People with Dementia [http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/CCP-Dementia-\(webv2\)\[1\].pdf](http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/CCP-Dementia-(webv2)[1].pdf)

Skills for Care (2012) Supporting dementia workers [http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Supporting-Dementia-workers-online-copy\(revised\).pdf](http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Supporting-Dementia-workers-online-copy(revised).pdf)

Department of Health (2009) Improving care for people with dementia <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>

10 Partnership working between the homecare workforce and other people working in health and social care

Five top tips for managers:

1. Be Courageous - really listen to what's important for successful integration from acute to community settings and visa versa then provide a unique flexible service – integrating day care with home care, respite service and rehabilitation services.
2. Create a workforce culture embracing positive social interactions - establishing a true relationship centred service – the Cardinal Healthcare philosophy is to develop a service ‘Matching your needs’.
3. Aim for continuity of care to develop a bond with the person and their family and to gain trust in exploring different ways to achieve daily living tasks.
4. Empower workers to be inspirational – to think ‘outside the box’, be flexible and communicate what works best. Comprehensive training and particularly the effective use of in-house dementia coaches is one very effective way of achieving this.
5. Ensure an ongoing commitment to support workers and relatives in practical ways to tailor care delivery to each person’s individual needs - each day is different!

Cardinal Healthcare has developed an innovative approach to integrated care which fully embraces the government’s ‘Shared Commitment’ to Integrated Care & Support. In partnership with Ipswich & East Suffolk CCG (IpESCCG) the programme has unleashed the potential of care in the community, hospital admission prevention and integrated discharge planning.

Partnership working focussed on how care pathways would be optimised, whilst at the same time being responsive to the specialist needs of individuals in areas including dementia, reablement and end of life care, particularly over the winter months to assist with avoidable hospital admissions, hospital bed blocking and integrated discharge planning.

Cardinal Healthcare Case Study

Two key considerations for all managers of homecare services for all individuals, including people with dementia are:-

- The effective delivery of person-centred care, and
- The effective management of individual and family expectations, particularly when the delivery of personal centred care does not match with what might have originally been expected from them.

To demonstrate these points, the following challenges may be familiar:-

- Being told to “Get out of my house, I don’t need any help!” when the reality is very different and the person with dementia does not realise this.
- Questions from families - why has my dad got a dirty pair of trousers on when I visited him today?

Explanation: the worker had spent some time encouraging the person to have a wash that morning but he wanted the brown pair of trousers on (which were stained where he had split something on them), but had not wanted to put the blue ones on even after gentle persuasion. Sometimes it is better to go with something that someone wants rather than making them distraught and breaking down the relationship and trust that you have with them.

- Questions from families – Why has the worker given my mum jam sandwiches for the past three days for tea”?

Explanation: the person had been offered a variety of foods but had refused to eat them so the carer had given jam sandwiches rather than nothing at all.

- Questions from families – Why is my mum still in bed and it is lunchtime?

Explanation: when the workers visited this morning your mum had refused to get out of bed, she was provided with a full body wash, had her breakfast, medication and was made comfortable and the carers said that they would see if she would like to get up when they visited at lunchtime. It is the individuals choice to get out of bed.

All the above are examples of where person-centred care has been provided, but families, rightly, still need to be reassured that we are working together and in the best interests of the person.

The challenge then is to achieve these aims, as well as the effective integration of health and social care services therefore it is of paramount importance that all parties feel listened to and the plan of care is openly discussed and agreed.

Cardinal Healthcare has been able to uniquely optimise partnership working across their Care centres, Day care and Home care services to integrate care pathways, to meet the needs of the individual and look ahead at the challenges around issues such a discharge planning, respite care, hospital admissions prevention, maintaining people in their own home for as long as possible and supporting and managing the expectations of Suffolk family carers.

Over the winter period, in particular, this partnership approach has even compassed weekly multidisciplinary team meetings attended by hospital consultants, social workers, hospital discharge planning together with the Cardinal team, all working together to ensure rapid

hospital discharges and reablement care. This taking place in either the care centre or in the person's own home in a 'virtual bed'.

General practitioners have also been able to utilise similar care pathways admitting direct to the centre, to prevent hospital admission or by redirecting patients assessed in accident and emergency and then being brought into the care centre for recovery and care prior to returning home independently or with a care package, day care or respite stays, and thus the full cycle of possibilities.

How this has been achieved

Employing workers with specialist skills, not normally seen in a community care service including occupational therapist, physiotherapist, physical therapy assistant, specialist nurses, dementia coaches, activity coordinators and the traditional home helps/ gardeners. Having such a diverse workforce Cardinal Healthcare has ensured all workers are well trained to listen and deliver care that is tailored to each person's individual needs.

The dementia coaches deliver a number of training sessions to all the team which has proved very valuable and "opened their eyes" to alternative ways to deal with difficult situations and has made workers 'think outside the box'.

One coaching session in particular is "Who is right?". Workers are asked to pick a character from a set of cards eg older person with Alzheimer's and then given a series of statements .eg 'Are you able to make a cup of tea unaided '?

For each of these statements the worker is asked to step forward when they feel their character would be able to carry out what was asked. People generally assume that a person with dementia "lacks capacity" to make decisions for themselves -"its not all about losing your memory and having every aspect of daily life taken a way from you" This training has given workers real insight into what life feels like for a person with dementia, how frustrating it is when carers come in and 'take over'

Gaining trust, friendship and building a mutual bond is the main aim from the "feelings matter most" training sessions and this has meant that the workforce has embraced the philosophy of building a truly relationship centred service.

Examples of Good Practice

- Creating 'Pockets of Opportunity' within the care environment to create positive social interaction and stimulate reminiscence and engagement in every day life.
- Therapists offering massage, aromatherapy , music therapy to reduce agitation
- Dementia coaches working with families to build a life story into the care plan and supporting all parties in understanding and improving communication and quality of life.
- Establishing a consistent team of workers for each individual to build trust and rapport when supporting daily personal care.
- Facilitating access to valuable ancillary services such as the gardener or home help to assist in all aspects of home life from emptying the bins to the weekly grocery shop with the person.
- Or a combination of any of the above – tailoring the support that's uniquely flexible including day care, planned respite stay, emergency respite (rather than hospital

admission) through to quick discharge and the reablement programme. ie anything from a regular day a week to assist with personal care, a weekend to a few weeks with physiotherapy continuing in own home. All this increases families coping strategies and continuity of care.

For the integrated service to be successful the whole workforce must truly grasp the philosophy of person-centred care and to create an environment which empowers workers thinking 'outside the box'

Relatives must be an integral part of this process starting from the moment you meet a prospective new person you may be supporting and their family in the initial assessment – “The best way to start is to find out as much about the person as possible, their background, likes, dislikes, preferences etc” and to put this into a personal Care profile which becomes a living document in progress, changing as and when needed to ensure each persons needs are met.

The benefits of such an integrated care approach – more stable workforce committed to increasing wellbeing, and far better relationships and interactions with the family, carer and the person with dementia.

Useful resources

- Growing -Training that works in dementia care (Feelings matter most series) (2008)
David M. Sheard

- <http://www.dementiacarematters.com>

- Norfolk & Suffolk Dementia Alliance – Comfort, compassion, Dignity

- www.skillsforcare.org.uk

- www.dementiauk.org

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Adapting home environments for people with dementia

Five top tips for managers:

1. Enhance quality of life and reduce behaviours that happen in Dementia by finding the right balance by adapting a home environment to suit the changes in a person with Dementia
2. Provide opportunities for more involvement in all daily living activities
3. Give workers the opportunity to be involved in adapting a person's home they are supporting by undertaking these activities with the person with Dementia.
4. Don't be frightened of asking for physical changes to happen to the person's home giving explanations of why you feel it would work better for the person you are supporting.
5. Be sensitive to changes that happen in Dementia, what's worked one week may not work the next. Don't be put off by this "get more creative"

Care Direct Salford tries to understand how Dementia affects people living at home and how making changes to the home environment can have real positive outcomes for the people they support. Meeting the changing needs of a person with Dementia by adapting their home environment can help them in retaining their independence and often manage behaviours that workers may find challenging. People with Dementia can experience loss and changes in several areas including:

- Memory
- Hearing, seeing, smell and touch
- How they see objects
- Managing and organising ideas for everyday living
- Behaviour.

Understanding and identifying what changes can be made to a person's home environment can create an environment which is safe and encourages a person to interact with activities that are fundamental to a person's wellbeing. Participation and occupation supports people with Dementia to still have autonomy which if done with the person in mind can reduce behaviours which may present as challenging to others. Research helps us to understand how Dementia affects the way people think and behave. Care Direct Salford assesses home environments to help them to meet the needs of the person with Dementia; they look at changes they can make to simplify all impacts the home has on a person.

Loss of memory can lead to confusion, agitation and a significant loss of independence. Our memory helps us to navigate our way around our environment, recognise night from day, know time and date, have conversations with people and ultimately recognise our home. Care Direct Salford promotes the person with Dementia to retain independence and control over their home environment by reducing the need for the person to ask repeatedly for missing information. The way they do this includes:

- Labelling cupboard and draws, helps a person to know what is contained within it, this reduces the searching that often causes distress.
- Using wipe boards to map out that particular day. Giving reassurance and visual comfort to help a person with repeated questions of what they are doing that day.
- Use of laminated pictures or written messages. These are placed around the home for example to navigate a person to the toilet or bedroom. Messages can be left at telephones, on fridges giving specific prompts.
- Using a memory box or life story book to trigger meaningful conversation.
- Using clocks which orientate to date, time, month, day or night.
- Highlighting in a magazine favourite television programmes and having a simplified remote control.
- Keeping the home calm and reducing the noise around the person you are supporting helps with communicating and the overall wellbeing of the person. Noisy stressed homes impact on people with Dementia and their ability to function.
- Talk in sentences that are easily understood and give the person time to respond to a question repeat the question if necessary. Talk in a clear voice addressing one point at a time.

Sensory changes come with age such as hearing and vision changes but at Care Direct Salford they assess if the person they are supporting has more difficulty in discriminating with colours, contrasts and smell for example. Some of the ways they can help a person manage these difficulties include:

- Suggest clutter is removed or unneeded furniture, so the person has easier movement around their home.
- Have brighter lighting in hallways and stairs or areas of the home that are used a lot by the person.
- Discuss having an extra grab rail for stairs to reduce the risk of falls.
- Be mindful of the sun coming through windows and causing shadows and unnecessary glare on objects that could be distracting.
- If a person is fixated with the front door and the repetitive locking and unlocking of it place a curtain over the door in a similar colour to the walls to reduce the anxiety (this would only be suggested if the person was living with someone else so access in an emergency wasn't hindered).
- Use the sense of smell to trigger hunger, cook foods which have a strong aroma to stimulate hunger and strong tasting foods stimulate taste buds.
- We all use touch to comfort, don't be afraid of giving reassurance through touch. Often stroking someone's hand sends a message of calm. Write support plans to include activities that give the opportunity to have this type of contact.
- Play soft music which the person likes.

Behaviour that may challenge causes major concerns for people with Dementia and their carers; it often can result in a person going into a Care Home. It adversely affects the person with dementia as often how we treat a person who we feel is challenging heightens behaviours and coping mechanisms within us all. Often labels are then attached to people who in hindsight may have been trying to communicate or get information they are missing due to their illness. Research shows that behaviour is the main reason for people going into Care Homes.

By adapting a person's home environment frustration and anxiety faced by the person with Dementia can be reduced. The environment should be carefully adapted to the changes and losses faced by the person with Dementia while preserving memories, experiences, interests and habits that are unique to the person.

Further dementia resources

In addition to the case studies and best practice identified in the guide, Skills for Care have also developed a number of resources to support the workforce working with people with dementia.

In particular the Common Core Principles for Supporting People with Dementia highlight the importance of a number of areas including effective communication, multi-agency working and signs and symptoms of dementia.

Skills for Care dementia resources are available from the following link:
<http://www.skillsforcare.org.uk/Skills/Dementia/Dementia.aspx>

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