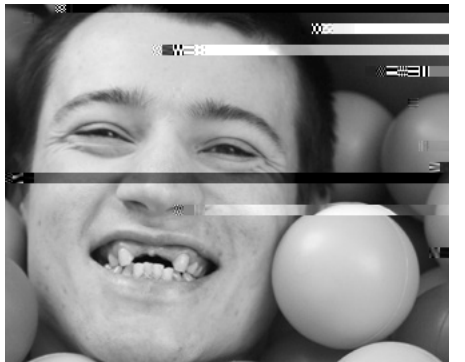


BUILDING A BETTER FUTURE





D C "

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

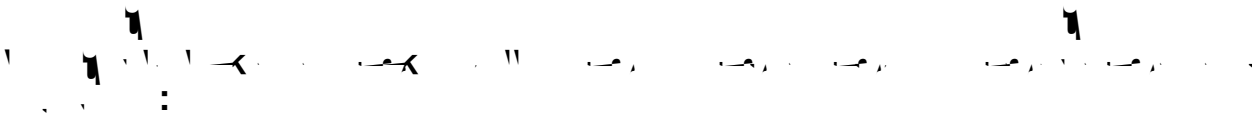
Skills for Care or contact us via email at: info@skillsforcare.org.uk.



Chief Executive Officer, Skills for Care



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Home Instead

Cardinal Healthcare

Meritum Independent Living

Cherish Care

Care Direct Salford

HomeCareDirect

Quality Care Home Services Limited

The Good Care Group

Ann Tuplin Care Services

DoCare

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

Published by Skills for Care, West Gate, 6 Grace Street, Leeds LS1 2RP
www.skillsforcare.org.uk

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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 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.

- 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.

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

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.



2. Local authorities and providers

2.1. Local authorities and providers

1. Local authorities should commission care services that are person-centred, safe, effective, efficient, equitable and accessible.
2. Local authorities should commission care services that are designed to meet the needs of people with dementia, their families and carers.
3. Local authorities should commission care services that are designed to meet the needs of people with dementia, their families and carers.
4. Local authorities should commission care services that are designed to meet the needs of people with dementia, their families and carers.
5. Local authorities should commission care services that are designed to meet the needs of people with dementia, their families and carers.

The **C** 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

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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.

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.

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.

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.



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.



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>

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>

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.



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.

۱۰. یاران و همکاران خود را در مورد بیماری خود آگاه کنید. اگر کسی از شما می‌پرسد که چه اتفاقی افتاده است، صادقانه بگویید. این کار به شما کمک می‌کند تا احساس بهتری داشته باشید و می‌تواند به دیگران کمک کند تا شما را بهتر درک کنند.

۱۱. با پزشک خود در مورد گزینه‌های درمانی صحبت کنید. پزشک می‌تواند به شما کمک کند تا تصمیم بگیرید که آیا درمانی برای شما مناسب است یا نه. همچنین می‌تواند به شما کمک کند تا با سایر گزینه‌ها آشنا شوید.

۱۲. اگر احساس می‌کنید که نیاز به کمک بیشتری دارید، با یک مشاور یا روانشناس صحبت کنید. مشاور می‌تواند به شما کمک کند تا با احساسات خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۱۳. با گروه‌های حمایتی صحبت کنید. صحبت با افرادی که با شما هم‌دردی دارند می‌تواند بسیار مفید باشد. این گروه‌ها می‌توانند به شما کمک کنند تا احساس تنهایی نکنید و راه‌های جدیدی برای مقابله با استرس بیابید.

۱۴. با یک مربی زندگی صحبت کنید. مربی زندگی می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۱۵. با یک مربی سلامت روان صحبت کنید. مربی سلامت روان می‌تواند به شما کمک کند تا با احساسات خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۱۶. با یک مربی تغذیه صحبت کنید. مربی تغذیه می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۱۷. با یک مربی ورزشی صحبت کنید. مربی ورزشی می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۱۸. با یک مربی خواب صحبت کنید. مربی خواب می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۱۹. با یک مربی مدیتیشن صحبت کنید. مربی مدیتیشن می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۲۰. با یک مربی یوگا صحبت کنید. مربی یوگا می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۲۱. با یک مربی تایچوای صحبت کنید. مربی تایچوای می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۲۲. با یک مربی هنر صحبت کنید. مربی هنر می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۲۳. با یک مربی موسیقی صحبت کنید. مربی موسیقی می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۲۴. با یک مربی باغبانی صحبت کنید. مربی باغبانی می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۲۵. با یک مربی سفر صحبت کنید. مربی سفر می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۲۶. با یک مربی آشپزی صحبت کنید. مربی آشپزی می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۲۷. با یک مربی زبان صحبت کنید. مربی زبان می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

۲۸. با یک مربی تئاتر صحبت کنید. مربی تئاتر می‌تواند به شما کمک کند تا با تغییرات زندگی خود کنار بیایید و راه‌های جدیدی برای مقابله با استرس بیابید.

4

4.1 Case study: Care Direct Salford

4.1.1 Summary of the case study

1. Care Direct Salford provides specialist dementia care services in people's own homes. The service is designed to support people with dementia who have challenging behaviours and are not engaging with other services. The service is designed to support people with dementia who have challenging behaviours and are not engaging with other services. The service is designed to support people with dementia who have challenging behaviours and are not engaging with other services.
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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.

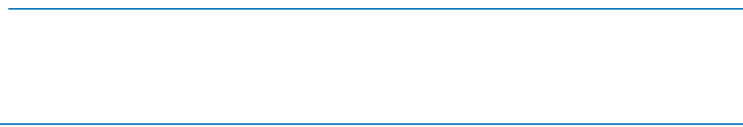
Effective communication is a foundation stone to how Care Direct Salford operates. Their purpose, vision and values all include participation not only from leaders but from workers, customers and people they support.

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.



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



5. Staff training

5.1.1. Staff training and education

1. All staff working in domiciliary care should receive appropriate training and education. This should include dementia awareness training, first aid training, fire safety training, and health and safety training.
2. All staff working in domiciliary care should receive ongoing training and education. This should include dementia awareness training, first aid training, fire safety training, and health and safety training.
3. All staff working in domiciliary care should receive training and education that is relevant to their role. This should include dementia awareness training, first aid training, fire safety training, and health and safety training.
4. All staff working in domiciliary care should receive training and education that is appropriate to the needs of the people with dementia they are caring for. This should include dementia awareness training, first aid training, fire safety training, and health and safety training.
5. All staff working in domiciliary care should receive training and education that is delivered by qualified and experienced staff. This should include dementia awareness training, first aid training, fire safety training, and health and safety training.

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

Better domiciliary care for people with dementia



• 2017 - 100,000 people with dementia in the UK. 100,000 people with dementia in the UK. 100,000 people with dementia in the UK.

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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.



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

6. What is the role of the caregiver?

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1. A caregiver is someone who provides care and support to people with dementia in their own homes.
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Specialising in non-medical care of older people in their own homes, Home Instead, **C** 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.

“What is your experience of how family members feel?” 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.

Better domiciliary care for people with dementia



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7.1 Personal budgets and direct payments

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Alzheimer Scotland 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:



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

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.



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?leID=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

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

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9.1 Meritum Independent Living

1. 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.
2. 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.
3. 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.
4. 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.
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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'

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.

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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.



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 _____

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Considerations

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

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.

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

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.



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

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.



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>

