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# Dementia: workers and carers together

A guide for social care workers on supporting family and friends who care for people living with dementia

Spring 2012

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“we help care workers develop partnership working”

in partnership with

**Dementia** UK  
Improving quality of life

 skillsforcare

## Preface

We are very pleased to introduce the latest of our products for the social care workforce supporting people with dementia and their carers. Skills for Care and Dementia UK have worked together in partnership to produce two products: this support guide *Dementia: workers & carers together* and an accompanying information resource.

Both products have been commissioned by the Department of Health and have been designed to be used together by colleagues across the social care sector to support collaborative working between the social care workforce and carers, leading to better quality care for people with dementia.

The products have been developed in co-production with carers to provide information, advice and guidance to the social care workforce, when working with the carers of people with dementia. They provide support for social workers, care assistants, personal assistants, people working in day care settings and well as others parts of the social care workforce.


Throughout the products there are a number of carer perspectives and examples, as well as links to further resources to support you and your organisation.

The products build upon the *Common Core Principles for Working with Carers* and level 3 of *Carers Matters : Everybody's Business* that have previously been developed by Skills for Care, in conjunction with Skills for Health. The products also build upon the *Common Core Principles for Supporting People with Dementia* – also developed by Skills for Care and Skills for Health. All the Skills for Care products are available at [www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)

We very much hope the guide and the information resource are effective in supporting you in your role. We welcome your feedback and comments on these products so please feel free to get in touch with Skills for Care staff or contact us via email at [info@skillsforcare.org.uk](mailto:info@skillsforcare.org.uk).



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## Acknowledgements

This guide has been developed by Dementia UK and Skills for Care and has been commissioned by the Department of Health.

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***Dementia: workers & carers together. A guide for social care workers on supporting family and friends carers of people with dementia***

Published by Skills for Care and Dementia UK

Skills for Care, West Gate, 6 Grace St, Leeds LS1 2RP [www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)

Dementia UK, 6 Camden High Street, London, NW1 0JH [www.dementiauk.org](http://www.dementiauk.org)

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Ref no. DS034

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Skills for Care is the employer-led strategic body for workforce development in social care for adults in England. It is part of the sector skills council, Skills for Care and Development.

Dementia UK is a national charity improving quality of life for people with dementia and their families. Dementia UK Training aims to develop the dementia care workforce through the provision of specialist training.

Bibliographic reference data for Harvard-style author/date referencing system:

Short reference: Skills for Care & Dementia UK [or SfC/DUK] 2012

Long reference: Skills for Care & Dementia UK, Dementia: workers & carers together. A guide for social care workers on supporting family and friends carers of people with dementia, (Leeds, 2012) [www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)  
[www.dementiauk.org.uk](http://www.dementiauk.org.uk)

# 1 An overview of working well with carers of people with dementia

Most care for people with dementia is provided by family and friends—‘carers’. The Alzheimer’s Society estimates the UK has 670,000 primary carers of people with dementia, and these carers save the UK £8 billion a year (Alzheimer’s Society 2012).

## Questions addressed in this chapter include:

- What is it like to care for a friend or family member with dementia?
- How does life change when you take on this caring role?
- What do carers want from social care workers?
- Which skills and qualities do this group of carers most value in the workforce?

This introductory chapter explores some key areas for supporting carers of people with dementia. The following chapters then highlight specific skills and approaches that particular parts of the social care workforce need to support the carers of people with dementia.

**A note on the word ‘carer’.** This guide’s main information uses ‘carer’ in its official sense to mean family and friends who provide unpaid social care support, as distinct from care workers. Caution is necessary in practice, however, because of the widespread informal use of ‘carer’ to refer precisely to care workers. In this guide, some quotes from carers reflect this alternative use of ‘carer’, particularly in references to “home carer” as a title for a domiciliary care worker.

## Life caring for someone with dementia

Carers of people with dementia have much in common with other carers, but in some ways their experiences differ. Studies show they live with greater strain and distress than carers of other older people (Moise, Schwarzingler and Um 2004). Caring often feels rewarding, and we can build on things that motivate carers, but there is also potential for physical and mental health problems caused by stress that caring for someone with dementia brings.

## Emotional strains of caring

Psychological pressures on carers of people with dementia are especially heavy:

- Frustration. Even in the early stages of the dementia, there can be frustration when memory varies and the person is unable to retain information.
- Stress, guilt and depression. Changes in the person and their relationship to the carer and others create emotional strain. Stress levels may increase, because the person may be unable to acknowledge their lack of capacity and may resist help, making it difficult for the carer to stay calm. At times there are distressing psychotic symptoms or behaviour changes that challenge the carer’s patience. Depression can set in when the carer is aware of all they are losing as a consequence of the dementia, and also as a result of the strain the caring role entails.

Guilt is common for carers who find they become irritable with the person's odd behaviour or constant questions, or resentful at feeling forced into a role they did not choose.

- **Uncertainty.** Life is unpredictable and no two days are the same. Despite meticulous planning, unexpected things happen and the carer has to cope with frustrations and disappointment. There is fear over the future. Will I be able to keep going? How will I cope with the later stages of the dementia?
- **Evolving feelings.** Initially there is the shock of adjusting to changes; as one carer puts it, in the early days she was in denial and unwilling to acknowledge there was a serious problem and "our anxieties banged up against each other and raised the temperature." Sometimes there is a phase where the person with dementia accuses the carer of hurtful things. Eventually the carer may face the pain of not being recognised by this person - perhaps who has been their life partner.
- **Feeling trapped.** The person with dementia may feel anxious if the carer is out of sight, so may follow them around the house. Carers are not free to come and go as they please, to pursue hobbies or see friends. Even simple tasks like shopping or attending medical appointments can be difficult. There are few breaks from the 24 hour responsibility. Short breaks to pursue interests or friendships can seem costly to the carer which might deter the caring from seeking opportunities to go out.
- **Conflicting demands.** Work and other relationships suffer. Left with inner conflict and resentment, they neglect their own needs. This is especially true where the person has young onset dementia and there are children living at home still.

### **Feeling lonely and isolated**

Often the carer has lost their closest supportive relationship because that person is the one with dementia. The parent or partner can no longer show concern for the carer or give the support they have relied on over many years. Carers struggle to shoulder all the responsibility and decision-making which was previously shared.

Other networks of friendship also diminish. The carer may have given up their job because of their caring role. Friends and relatives may stop visiting because they find the situation difficult. Sometime the carer's decisions are questioned by friends and family members who don't see the full extent of the difficulties posed by the dementia; it can be deeply painful to face criticism for doing what you believe is in the person's best interests. It can also be difficult to go out because of financial constraints and anxiety over how others will respond to unusual behaviour.

Carers often feel they are the only one going through this experience, that no one understands. Sometimes personal dignity or not wanting to be pitied can cause carers to 'put up a front' as someone who copes.

### **Practical demands of caring and the risk of exhaustion**

Caring for a person with dementia has many elements. Emotional support and reassurance for the person are key at all stages, but early on the carer has also to take on many practical tasks such as looking after the house and garden, shopping, and taking care of finances. As the dementia progresses, more care is needed. The carer's role goes from prompting and reminding to giving more and more help with eating, washing, dressing and going to the toilet. Extra effort needed to maintain communication can be very tiring. As one carer put it, "Much of my energy was spent trying to interpret him to the world, and the world to him."

In the later stages, mobility, continence and swallowing difficulties can lead to the person needing a great deal of help with personal care, as well as extra washing and food preparation. There may be anxiety over the health and safety of the person with dementia, the pressure of continually needing to assess risk, living in a constant state of high alert. Often, this is happening at a stage of the carer's life when energy levels are lower.

The physical demands might be manageable if sleep were guaranteed, but many carers have broken nights because dementia disrupts their relative's sleep patterns, perhaps resulting in anxious or obsessive behaviour during the night. For carers who don't live with the person with dementia, there may be the stress of continual 'phone calls at all hours of the day and night and the carer rarely feeling relaxed. Finally, financial pressures are common for carers who may have lost employment and face extra costs caused by the dementia.

### **Feeling ill-equipped and unsupported**

Most carers feel unprepared to take on this new role. How can you feel confident as a carer if you lack the basic information about dementia that will help you understand what is happening and how to respond? At the point of diagnosis many carers are not in a position to absorb information they are being given about dementia symptoms, strategies that can help and local sources of support.

Many carers struggle to accept help. They may feel they should be the one providing all the care and no one can care for the person as well as them. Or the person with dementia might be against involving anyone beyond the family. Other family members may dislike the perceived stigma of needing outside help.

### **Wanting to care**

Despite the pressures, there is a desire to care and a motivation to do the best for the person with dementia. Satisfactions of caring vary from carer to carer, but common themes include wanting to repay the kindness received over many years from the one who now needs support, and the opportunity to be close to the person and protect them. Those who support families can acknowledge this desire to care and help maintain the rewards caring brings.

### **What do carers need from care workers?**

Some key points for workers supporting the carers of people with dementia.

- Respect the carer as an equal partner with you. They know the person with dementia best and have discovered strategies that work. People working in social care should work corroboratively to find the best solutions.
- Listen to the carer and find out how they are coping. Recognise that the carer may say they are 'fine' and appear cheerful while underneath they are struggling. Pick up on stress signals through questioning and observation.
- Remind the carer that they have needs too. Encourage them to take time to rest and relax. If they are struggling to accept breaks, help them see benefits that might come for them and the person they are caring for. Be knowledgeable about the help available and share this information.
- Be sensitive to difference and don't make assumptions. Not all relationships are the same. What is the nature of the relationship between the carer and person with dementia? Be aware of how differences (of race, religion, sexuality) are relevant to the caring situation. Even simple things, like forms of address you use, can show your understanding of cultural differences.

- Recognise the reasons a carer may be abrupt or impatient. We make allowances for the person with dementia, but we also need to recognise the strain carers are under which might occasionally make them a little less polite than normal. Carers have to be insistent at times to achieve the best for the person for whom they are caring; their role includes being an advocate.
- Avoid being judgemental. Each carer finds their own way of coping within their limitations.
- Be flexible and open to exploring alternative solutions. Thinking creatively leads to better outcomes for a person with dementia and their carer.
- Use appropriate communication methods.
- Many carers are not online, so emails are not a good way to reach them. Mobile phone conversations can be difficult too if you catch the carer in a public situation and try to address confidential care matters; ask the carer if it is a good time to talk.

What carers of people with dementia look for in social care workers:

- Knowledge and experience of dementia and available resources.
- Good communication and listening skills.
- Ability to be flexible and proactive.
- Ability to share ideas and co-operate with the carer.
- Good time-keeping and reliability.
- Ability to detect triggers, likes and dislikes, in a person with dementia.

### References

Alzheimer's Society (2012) *Dementia 2012: A National Challenge*.

Moise, Schwarzinger and Um (2004) *Dementia care in 9 OECD countries: a comparative analysis*, OECD Health Working Paper no. 13, OECD: Paris



## 2 Day care centre staff

**Carer's perspective:** "A positive relationship was built with my mother's day centre. Regular reviews were held with the assistant manager and my mother's named carer, and exhibitions were held of her art work. Attendance at the centre facilitated her to be seen and reviewed by her GP on the premises."

Day centres provide quality time for the person with dementia and invaluable short breaks for their carers. Having a few hours to get on with other tasks or have a rest can make a world of difference to carers.

### Getting to know the person with dementia and their family

In order to care for the person with dementia, you need to understand them, and the carer is usually the one who knows them best — they are the expert on that person. As well as meeting with the carer, you could ask them to write down things that will help you; from likes and dislikes, care needs and health issues, through to biographical details and interests. This will enable you to tailor the support you give, acknowledging how much the person can do independently and seeing what help is needed, as well as gaining an insight into activities that will provide enjoyment. Ideally at this time a life history book could be made, with the help of relatives and other members of staff.

How about inviting the person with dementia and their carer to visit the centre first? Or you could arrange to see them at home: observing the person with dementia in this environment will enable you to understand them better.

### Working with carers as partners

**Carer's perspective:** "I was very anxious the first day I took my husband to the day centre. I remember walking away from the day centre with tears in my eyes, feeling just as I had when my children first started school."

Accepting day care is particularly difficult for carers of people with dementia. It is hard to explain to the person and prepare them because of their difficulties understanding and remembering; they might be resistant to the idea and need persuading. The carer feels especially protective of a relative with dementia, so they need reassurance that the person is going to be safe and happy.

### What can you do to reassure carers?

- Suggest the carer explains to their relative with dementia that they have essential tasks and errands to do, rather than saying they will be resting or going out while they are at the day centre.
- The first time the carer leaves the person is particularly difficult. It is important that both the person with dementia and their carer are supported with this.
- Encourage the carer to ring the centre if they want to know how the person is finding their day.
- Ensure the person goes home with a summary of the day, including positives and any issues. Engage the carer with helping to find the solution to any challenges.
- Offer regular opportunities for the carer to meet with senior staff and the named worker for their person, to exchange information and plan together.

Carer's perspective: "On the day I first took my husband to the day centre, we were greeted immediately with a warm welcome. The workers always made sure my husband was happily absorbed in some enjoyable activity when I was ready to take my leave. At one stage, things became rather difficult and my husband was reluctant to leave home with me to go to the day centre. Fortunately they had a most understanding outreach worker, and when I phoned to explain the position, she drove over to our flat and persuaded him to come with her to the centre. I appreciated the flexibility, initiative, imagination and willingness to literally 'go the extra mile'."

While the person is with you at the day centre, you might be able to provide aspects of care that are difficult for the carer at home, such as helping them have a bath, a shave, or a haircut. What happens during the time at the day centre can either help or hinder the carer. If you help the person experience wellbeing and retain abilities, this will have a positive impact when they get home. If the person is frustrated or over-stimulated, the carer might be left picking up the pieces. Give plenty of warning should there be plans to discharge a person from the day centre; it will be a great shock and a huge loss if it is done suddenly without warning. Carers need to make other plans.

### Showing sensitivity

It is important to be aware of how the carer and the person with dementia wish to be addressed and respecting this is particularly important if the family is from a minority ethnic culture where social etiquette is different. Be especially tactful when telling the carer about any problems, or the carer can feel they are being blamed. Remember that they want to hear about highlights, not just problems and challenges. Praise achievements with positive, supportive language and avoid any negative language.

Carer's perspective: "I received a phone call from my husband's day centre, asking me to pop in briefly with another cardigan, as juice had been spilled on the one he was wearing. As I was leaving, the manager called me into the office.

"Out of the blue, the manager described recent incidents when my husband had touched female staff members, implying he may not be able to stay at the centre. I felt I had prepared staff for this possibility and suggested strategies to minimise the risk, but I also felt my advice and suggestions had been ignored. Had I known they were going to raise this difficult issue, I would have asked a friend to support me."

### Involving carers in the day centre

Although your service exists to give them a break, carers may like to be involved from time to time. You could:

- invite carers to special celebrations, such as cultural or seasonal events
- hold regular support and information sessions for carers
- have coffee mornings to help carers meet each other
- involve carers in staff training sessions on dementia .

Carer's perspective: "The day centre held information sessions for carers, inviting outside speakers to come and talk about topics. I found out about the council tax reduction for people with dementia at one of these meetings. Nobody else told me we might be entitled to this help. It made a big difference to our lives."

## Transport matters

The journey to the day centre is an important part of the experience of attending a day centre. Transport staff need to know how to respond to people with dementia, using skill in gently coaxing a person who is reluctant to get on the bus and helping them feel settled during the journey. It will also help if they keep the carer informed of when they are hoping to arrive and if they are delayed.

## Key tips for day centre staff

- Value and use the carer's knowledge of the person with dementia.
- Recognise and respond to the carer's feelings of anxiety.
- Communicate regularly and meaningfully with carers.
- Help carers feel part of the service by inviting them to occasional events.
- Be sensitive to the carer's feelings in working through any problems.
- Be punctual in collecting and returning the person with dementia.



### 3 Domiciliary care workers

Providing support in a person's home is different from caring in a public space. Many of the attributes carers look for in a domiciliary care worker are to do with the fact you are going into the home as their guest.

#### Knowing the background

Carer's perspective: "My mother's memory and mental state had been declining for many years, but she was never willing to acknowledge this. I gradually assumed responsibility for everything in her daily life. In time, her psychiatrist and social worker could see she needed help in the home. We hoped the occupational therapist might be a way into this – persuading her a home help for domestic tasks might be a good idea, now she was over 80 and more physically frail – but she didn't buy it. She was adamant she was fine, and irate at the suggestion she couldn't manage."

There may have been a long, tense process of gradually accepting help is needed in the home. The person with dementia may dislike the idea of strangers coming into the home and believe family members should be the only ones looking after them. This is especially true in cultures where the idea of family responsibility is very strong. The carer may also resent the idea that they can no longer manage. Your first challenge will be to show you can be trusted and that the help you can bring makes a positive difference.

Another aspect of knowing the background is being well informed, so you can show sensitivity and give appropriate help. At the beginning of a visit, find out what the person with dementia needs, what kind of day they are having, and how you can best support the carer. Learn about relationships in the home, picking up how members of the household get on and express themselves. You may be aware of conflicts and tensions. Try to avoid making value judgements, unless you feel the person with dementia is at risk.

#### Respecting the home

You have only to think how you feel about strangers coming into your home to realise the psychological effect on the carer and the person with dementia of opening up their private space. Act as an invited guest, finding out how the family want you to treat their home. Ask about routines and habits, and fit in with these. Learn about any 'house rules' you might need to observe. Think about how you address the person with dementia and their carer; there is a fine line between friendliness and over-familiarity.

When working in someone's home, you should try not to do things that will alter the state of the home, like moving things or leaving a mess. Be aware of other people who live in the house and respect each household member's privacy.

Consider carefully how you dress; some clothes may not be appropriate in households with particular beliefs or where a person with dementia has reduced inhibitions. Be vigilant about maintaining confidentiality. Only share information that you need to share with other people. Be careful not to bring unwanted odours into the house, such as a strong perfume or the smell of cigarette smoke which may linger.

People with dementia sometimes accuse visitors to the home (including relatives) of having hidden or stolen items. This may be because the person has forgotten where they put things. It might be useful to devise a strategy with the carer for ensuring all items of value are locked away safely.

If you are at the receiving end of such accusations, try not to take it personally and recognise it is connected to the dementia.

Carer's perspective: "If only the home carers would take their shoes off when they come in. I don't like to ask them because they might think I'm being fussy and take it out on my wife, but the stains on the carpet are really getting me down."

Carer's perspective: "She came bustling in and turned the radio off. It had taken me ages to settle Dad with the soft music he likes so much. The home carer said it was boring, but Dad soon got restless when he couldn't hear the music."

### Being a friend

Carer's perspective: "A young man who was studying law gave my husband personal care at home over quite a long period, so we got to know each other well. He always managed to raise our spirits when he arrived at the flat, and he would give me reassurance and encouragement if I seemed distressed, always with a smile and sensible words. When the time came for my husband to go into the care home, this kind young man knew how upset I was about it, and made special arrangements with his agency to alter his schedule so he could accompany us in the ambulance to the home, helping him down the stairs and providing cheerful company all the way. I will never forget him."

Although you have to work within professional boundaries, in time you will become a familiar face, and the carer may look forward to seeing you, as one of the few people they speak to on a regular basis. Remember to look out for signs of when they are struggling and the situation is deteriorating. It will be easier for the carer to accept your help if they feel the relationship you are building enhances their relative's life. Carers want domiciliary workers to show warmth and engage their person with dementia in conversation as they are providing care. For example, the photographs you may see around you can provide an opportunity to ask and talk about grandchildren and the

extended family and support the discussion of the life story of the person with dementia.

Carer's perspective: "I like it when people who come into our home talk to my husband and listen to what he is saying, or trying to express, even if it seems inappropriate or rude. Above all, I want them to enjoy the time they spend with him."

### Teamwork

Think of your role as being to work as part of the team with the carer. They are the one providing most of the care, and you are coming in to lighten the load.

- Find out from the carer what would most help them.
- Be flexible.
- Let the carer know if you are delayed but don't make them feel you will be extra rushed with them as a result — reliability is key.
- Don't be critical or judgemental of the carer if they do things differently, but find tactful ways to suggest alternative strategies you think may help.
- Be aware of other sources of help the carer can tap into.
- Inform the carer about what happened in your visits, feeding back positive as well as any challenges.
- Notice and record anything that changes and might indicate new needs.

Carer's perspective: "I am looking for compassionate staff, who listen and try to make things easier for me as the carer. I also think it is important that home carers are briefed about the condition of the person they are to care for, so they know what to look out for."

## Remembering carers who don't live with the person with dementia

Not all carers live in the same household as the person they look after. This is especially true for sons and daughters caring for parents. They might live in the same town or a considerable distance away, but they are providing a lot of support and need to be informed of the domiciliary worker's visits. This might be through 'phone calls, emails or text messages. Using a communication book in the person's home might help in some situations, though there is a risk the person with dementia will tidy it away or be confused or distressed by what is written. Talk to the carer about how best to keep in touch with them, as each person will have their own preferences.

## Top tips for domiciliary care workers supporting people with dementia

- Find out as much as you can before you visit, so you are prepared.
- Treat the home as you would want a visitor to treat your home.
- Build a supportive, respectful relationship with the carer.
- Notice anything that is changing, including the carer seeming stressed.
- Find ways to complement the carer's role and make their life easier.
- Don't forget the needs of carers who live in a different household.



## 4 Personal assistants

Personal assistants (PAs), or people employed directly by people with dementia and their carers, usually work in the home of the person with dementia, so many of the principles from chapter 3 apply equally to this role.

Respecting the home, and learning about relationships between the people who live there, are necessary skills for personal assistants as well as domiciliary care workers. But personal assistants work in a different way to enable the carer in their role supporting the person with dementia.

**Carer's perspective:** "Our PA was vary varied in terms of what they did. He went along to reminiscence sessions, took my husband to the tip to get rid of rubbish from the garden, helped walk the dog, cut the lawn, or supervised any of these activities if my husband was having a good day. The reason he made such a difference is, even a trip to the local tip reminded my husband he could still do normal things, which in turn increased his self esteem. Because he has known my husband as long as I have, the memories they share go back many years.

"This allowed me to relax, knowing that my husband was safe and entertained. The personal assistant also filled in a 'day sheet' which told me on arriving home where they'd been that day, what they had done, what my husband had for lunch, anything that had upset him, if he had slept at all, how noisy or quiet the day had been for them..."

### Being flexible

The job of personal assistant is broader than most roles in social care, because it encompasses whatever is needed to support people with dementia to live as they want to. Rather than undertaking a limited set of tasks, such as helping with personal care or eating, the personal assistant might also help the person maintain interests and friendships, go on holiday, look after pets, go shopping or attend appointments. They need to be versatile and creative over how they use their time, and flexible over availability.

Another key difference from other social care roles is that, under personal budgets and direct payments, or through private arrangements, the personal assistant is employed directly. In the case of people with dementia, the family carer is usually the employer, responsible for defining the role and providing necessary training and employment safeguards. A further distinction

is that many personal assistants work with just one person, or possibly with a small number of people with dementia. They spend longer periods of time with the individual(s) and are able get to know them well. This depth of knowledge about the person, and sensitivity to varying moods and abilities, enables the personal assistant to adapt to the needs of the person they are supporting.

You will be most effective when you discuss with the carer how your contribution will best fit around the carer's role, so that you work as a team to achieve quality of life for the person with dementia. It is important to clarify the carer's expectations, offer suggestions and give constant feedback on what has worked well and any difficulties. Discover biographical information to help you plan activities, and share your ideas with the carer who is ideally placed to advise.

Doing practical tasks can help the person with dementia to feel you are there for practical reasons and may reduce their feeling that they are being 'minded', which might cause some frustration in the first few days of the role.

A carer's perspective reported : "The PA soon learned that part of the role the carer wanted her to fulfil was to act as advocate. When Mavis was out visitors sometimes called at an inconvenient time, such as when Ron (the person with dementia) was resting, having a meal or receiving personal care. With Mavis's permission, the PA would tactfully ask the visitor to return at a more suitable time."

### **Keeping up-to-date with best practice and linking with local groups**

When you work for an organisation, they are responsible for making sure you have the right training for the job. If you are a personal assistant, the carer might send you on training, but you may also have to be proactive in finding suitable courses and other ways of learning. In particular, you will need to find out about dementia:

- how best to respond
- person-centred approaches
- progression of dementia
- extra prompting and support

This will help the carer feel confident in your capacity to support their relative in the right way. A good place to seek advice for relevant training is your local authority or from Skills for Care ([www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)).

You might also benefit from linking in with local organisations that support people with dementia. They might offer courses or be able to advise and support you, and they might also run groups, outings and other social opportunities for people with dementia in which you could help the person you are supporting participate. You will meet other people who are in caring roles

and have a chance to share experiences and ideas. You may be able to forge some informal friendships which will widen the social network of the person you support.

### **Being someone the carer can rely on**

Your role may enable a family to have a more settled routine and back-up in emergencies, so it can contribute in no small way to peace of mind. It is essential the carer can rely on you, so if you are going to need time away (e.g. doctor's appointment), give the carer as much notice as possible so they can make alternative arrangements.

Carer's perspective: "My mum's assistant was not employed through an agency, so she was able to undertake tasks which might otherwise be prohibited, such as changing a light-bulb, or picking up shopping. She took Mum out for pub lunches, which she really enjoyed as she could no longer go out safely to meet friends if I wasn't there. The reason the relationship worked so well was largely down to her personality and tact. She is very warm, friendly and humorous, chats easily and is able to understand the psychology of those with dementia, as her own mother had Alzheimer's."

"She agreed to visit two or three times a week, for a couple of hours at a time. As arranged with me, she would generally arrive at lunchtime, to make sure my mum had something to eat. She would keep her company, provide reassurance and cheer her up from any depressive episodes—and would report back to me with any concerns. She also held a spare set of keys for the many occasions Mum locked herself in or out of the house. She was flexible about exact times and length of visits, and could go round in emergencies."



### Top tips for personal assistants

- Keep as your focus helping the person with dementia live their life.
- Be a reliable, trustworthy presence for the family.
- Find ways to update your knowledge and skills in dementia care.
- Link in to local social and support networks.
- Be flexible and creative over how you spend your time.
- Share your ideas with the carer and listen to their advice.
- Give the carer a summary of the time you have spent with their relative.



## 5 Voluntary organisation workers

Voluntary organisations play a uniquely valuable part in supporting carers as they can be flexible in reaching out to carers of people with dementia.

Carer's perspective: "The manager of the voluntary organisation's day centre took me into her room the first time I left my husband and spent time with me. She taught me more about dementia on that occasion than anyone had in the several years I had been struggling to look after him. She arranged for me to attend the next meeting of the voluntary organisation's support group and put me in touch with an Admiral Nurse [a specialist dementia nurse who works with family carers]. The voluntary organisation also developed a Family Care Team—I spent five years as a volunteer supplementing their work by means of regular phone calls to several carers. Then the voluntary organisation's social worker helped me find a suitable care home and came with me the day my husband was admitted, driving me home afterwards."

### Helping carers find a voice

The carers of people with dementia often feel that no one sees the pressures they face. Voluntary organisations help these carers recognise they are not on their own, and can work with them to achieve recognition and better services. Because they are independent, voluntary organisations can help carers to be assertive and advocate on their behalf. Local voluntary organisations support carers individually to gain help to which they are entitled, supporting them at meetings and helping them fill in forms; they stand up for neglected minorities, like carers from black and minority ethnic groups or travelling communities. Helping carers speak up for themselves is a key contribution voluntary organisations can make.

Carer's perspective: "The Black and Minority Ethnic Support Group offered information from invited speakers, provided advocacy, and gave me a most valued sitting service of four hours a week. It was instrumental in organising conferences for carers, giving us an opportunity to challenge directors of older people's services and make their voices heard."

### Keeping carers connected

Caring for someone with dementia can be socially isolating. Dementia 2012, the Alzheimer's Society annual report on the

circumstances of people with dementia, highlights how easily friendships fade away after dementia is diagnosed and how lonely people with dementia can feel. Voluntary organisations are key parts of the local community, a place where carers and people with dementia can feel they belong and are among friends.

A common activity for local voluntary organisations is running support groups and other social contexts where people with dementia and their carers can meet each other and build self-help networks. Support groups help carers offload difficult feelings and share things they are finding hard. Cafe-style events are also valued opportunities for people with dementia and their carers to socialise with others in the same situation. This is known as 'peer support' and is one of the priorities of the National Dementia Strategy (DH 2009); most peer support is in fact provided within voluntary organisations.

Some voluntary organisations, both locally and nationally, provide telephone support to carers of people with dementia who find it difficult to leave the house. This can be a lifeline. 'Talking Point' is an on-line forum run by the Alzheimer's Society where carers of people with dementia share problems and ask for support and other carers are able to suggest tried and tested ideas. It is greatly valued by carers as a

24-hour service to which they can turn, even in the middle of the night.

Carer's perspective: "The worker was extremely enthusiastic, supportive and passionate about the carers' support group. I felt part of a small family, nurtured and understood. I gained insight, information and most importantly was not judged for my lack of knowledge and seeking tips from those who had been caring longer than me."

### **Making time to listen**

One of the ways we can most help carers of people with dementia is by being a good listener. Carers sense that voluntary organisations have time for them as an individual. The carer can talk through their feelings and questions in detail, and this is a real safety valve. Because the focus is on listening to the carer, voluntary organisations are good at responding flexibly with services that meet their needs; innovating, filling gaps and doing things in ways that reflect their local community. Think about ways your organisation's volunteer befrienders, listeners, or counselling service could be offered to people with dementia and their carers.

### **Providing information, training and advice**

Local voluntary organisations for carers often provide opportunities to learn about aspects of the caring role, such as back care and first aid. Particularly in the early months after a diagnosis, carers value opportunities to find out how dementia affects the brain and changes they might see in their relative. Written information about dementia and details of services that are available can also be a great help. Voluntary organisations are more able to be clear about rights and entitlements than local authority staff who may be limited by local budget restraints.

Carer's perspective: "The local Carers' Centre has been the most important support for me. This is because my concerns were treated seriously, and when I needed information and emotional support I was offered a support worker to sit in on assessments and help me fight my corner. Because she understood the system, she could simplify the processes for me. And the dementia course they ran offered me a different way of looking at things."

### **Caring for the carer**

Carers appreciate simple efforts to show care and concern towards them. In your community group or voluntary organisation, remember to ask after the carer and not just the person with dementia they are caring for, and show that you realise the emotional stresses life can hold for them. Activities that provide carers with moments of relaxation and enjoyment are greatly appreciated. By providing a meal, arranging an outing, offering massage sessions, or inviting carers to special events, you help the carer feel their needs are acknowledged.

Carer's perspective: "The voluntary organisation running the reminiscence project had sessions for people with dementia and their carers. A wife in the group seemed rather ashamed of her husband's dementia. I remember one week when they were asked to talk about their previous work. The husband stood up and told everyone about his life as a docker, and for the first time we saw the wife looking proudly at him. The staff working in the project showed respect, friendliness and enjoyment in their tasks, which made a wonderful enabling atmosphere."

### Key tips for voluntary organisation staff

- Be a friend and an advocate, helping the carer access help.
- Provide opportunities for friendship and socialising.
- Cultivate listening skills and make time to listen.
- Help resource carers through information and education.
- Find ways to support the carer—simple things that make them feel special.

### Who are standards for?

*Dementia 2012: A National Challenge*, published by the Alzheimer's Society, March 2012.

*Living Well with Dementia: A National Dementia Strategy*, published by the Department of Health, February 2009.



## 6 Local authority workers in carer support roles

Carer's perspective: "Two years ago, when I was caring for my mother who had dementia, I took up the role of carer co-chair of our local authority's Carers' Partnership Board. The board is a forum for carers to be involved in decision-making and influencing change. I have also been part of a scrutiny panel, looking at what services are available for carers within the borough and their accessibility, identifying gaps and how these can be met, and turning rhetoric into reality. We obtained funding for a 'hub' at one of the libraries where carers can access information, help and activities from other organisations. Recently carers were invited to be part of a presentation on carers' issues held in the Council Chamber and they were also given public recognition of their role as carers."

Local authorities employ staff in a variety of roles to support carers. Specific roles and tasks vary from council to council, but there are underlying principles for meeting the needs of carers of people with dementia.

### Ensuring carers are represented

Ensuring carers' needs are identified and met is a key local authority responsibility. Your role might include encouraging carers of people with dementia to take up active roles representing others in their situation. For some carers, this opportunity to speak out and contribute to a better life for other families is highly motivating. Most local councils hold regular forum meetings where carers can express their views and influence service provision. How might you ensure that the voice of carers of people with dementia is heard at such meetings? Are you able to provide a support service so these carers can come to meetings?

You will need to be aware of carers who are easily forgotten, those in a minority because of differences like race, culture, religion or sexuality; these carers need to be represented in service planning. Carers supporting relatives in rural areas face special challenges in accessing help, so making sure they are consulted and included is important. Carers in Asian families can be reluctant to acknowledge an older person has dementia, perhaps because of the stigma associated with mental health problems. They tend to struggle alone until crisis strikes. Part of your carer support role will be to learn about and

promote awareness of dementia in minority communities. Outreach to these groups by the local authority can build awareness of the need to accept help from outside the family.

### Helping carers access help

Your role is likely to include helping carers of people with dementia to find out about Carer's Assessments, making them aware of their rights, and telling them about options for respite care or help in the home. It might also cover support for carers to remain in employment or to access leisure or adult learning opportunities. You will need to be knowledgeable and up-to-date, both about the distinctive needs carers of people with dementia face and local services. Some carers don't recognise their role as 'carers' and often don't like to be referred to as a carer – they see themselves as a wife, a son, a grandchild – and your role might be to find these 'hidden carers' of people with dementia.

Carer's perspective: "The local authority carers' support worker was excellent. She really tried to build relationships with carers and people with dementia. She would take them shopping, visit them at home, be with them when they saw the doctor, and became a valuable lifeline for the carer. She helped the carer by trying to understand the situation fully, and reporting this back to the care manager. She was friendly, professional, respectful and knowledgeable."

### Providing support

Some local authorities run support groups for carers of people with dementia. This provides a welcome opportunity to express feelings and explore strategies. There may be an educational element to the group, with invited speakers addressing relevant subjects.

Carer's perspective: "I was fortunate enough to be given information about the local carers' support group, which was run in the evening—a godsend for carers like me who work during the day. Once a month they met up and had supper, quizzes, karaoke sessions or other activities. I will always remember the kindness of the helpers. They were a vital lifeline, a fantastic source of information and it was a great social outlet for me."

### Helping families receive personalised support

People with dementia and their carers have been slow to embrace the opportunities offered

under personal budgets. Personalisation may offer greater flexibility in finding sources of support that are acceptable to the person with dementia. The disadvantage for older carers is the extra complexity and additional responsibility (in employing personal assistants, for example). An important contribution you can make might be explaining how this new way of working can be beneficial, helping dispel myths and overcoming anxieties.

### Key tips for local authority staff

- Make sure the voice of local carers of people with dementia is heard.
- Be a source of up-to-date information for carers.
- Identify how best you can provide networks of support.
- Find the hidden carers and help their needs to be recognised.
- Encourage carers of people with dementia to explore personal budgets.

## 7 Residential care workers

In the later stages of dementia, full-time residential care is often needed, although this is not always the case. For many carers the decision to put their relative in residential care is one of the hardest life choices they have ever made, as one carer of a person with dementia notes, “It felt like I was abandoning him.” It is vital that staff working in residential settings work closely and supportively with carers. Some of the factors for staff to consider are noted here.

### Showing empathy

Carers use strong words to describe how it feels to hand over the fulltime caring role. “It was the worst day of my life” is often said of the day they left their person with dementia in the care home. Feelings can be complicated and painful:

- Worry and uncertainty – over whether their relative will settle and how they will respond; whether staff will understand and give the right care; whether they will be able to find a new caring role.
- Guilt and doubt – over whether they could have done more to keep the person at home; over whether the care they gave up to this point was good enough; over the sense that they are ‘abandoning’ the person or breaking promises they made in the past that they would not allow the person to go into a care home; over having to deceive the person to get them to come to the care home.
- Grief – over the finality of the move to a care home; over going back to an empty home; over loss of role and the life together that has now ended; over changes in the person with dementia and them pleading to go home.
- Exhaustion – especially if the move came at the end of a stressful period, or after a crisis in the health of the carer or the person with dementia. The carer may feel worn out and possibly quite unwell, after many years of caring.

- Loss of role – from being the person involved in everything, they face handing over their role and decisions to the care home. It may seem as if they resent you or feel threatened by your relationship with their relative.
- Relief – hard though it may be to admit, most carers feel relieved they no longer have to cope with pressures that had become intolerable.

Painful feelings are at their most intense in the early days. Setting aside time to listen and reassure will help carers, as will allowing time for the carer to see they can trust you with the care of their relative.

*Carer’s perspective: “Leaving your relative in the care home for the first time is hugely traumatic. I was sick with nerves waiting for the moment for me to leave Mum that first day, anxious to avoid a scene. This feeling has not improved much in the six months since. On a good day, staff are on hand to distract my mum so I can slip out discreetly when it’s time to go. However, at weekends they are often busy with other things, so leaving after a visit remains a major trauma.”*

### Working in partnership

*Carer’s perspective: “It would be helpful if staff check that the carer has all relevant information about the routine of the unit— clothes being name-taped, arrangements for booking to have meals during visits or taking them out, doctor’s appointments, ways to personalise the bedroom, activities that happen on a regular basis...”*

The carer knows the person with dementia better than anyone, and can help you learn about their personal history, sharing with you their needs and strategies for supporting them. They may also wish to continue with practical aspects of the caring role, such as helping the person at mealtimes, and this is to be encouraged. They will value the knowledge and skills you can share, particularly as the dementia progresses. Understanding the relationship between the person with dementia and their carer will help you to keep the bond strong. The experience of separation is different for husbands, wives and partners than it might be for sons and daughters; try not to assume that everyone is going through the same thoughts and feelings, as every relationship is different.

It is good practice to use life story resources in getting to know new residents with dementia. Ask the carer to put together an album, scrapbook or memory box with photographs of key people and descriptions of the person's life, or help them put one together. When the life story resource is finished, make sure it is well used to help everyone understand the resident.

*Carer's perspective: "I have noticed that the care home staff ask for information on the person with dementia and then initially ignore the help you have tried to give. Then when they have a bad day, they realise your coping strategies really do work. I realise they have far more experience in the field than I do, but I have more experience of my husband than they do, and I know what works for him as an individual."*

### **Keeping the carer informed**

It is difficult to go from knowing everything that happens to the person with dementia to feeling out of the picture. Part of a keyworker role is to discover how the carer would like you to keep in touch with them. If they visit regularly, you can exchange news when they are in the home, but if they live at a distance they might like you to ring them on a regular basis with an update. Be honest with the carer, not hiding

any problems but discussing with them ideas for overcoming difficulties.

*Carer's perspective: "I have every confidence in Mum's care workers, but I am conscious of not wanting to interrupt them in their tasks when I am there, or appearing to be a nuisance on the 'phone. When my mum first went into care, the manager told me that they would not call me unless there was a problem, which was a relief at the time. But now it is strange not hearing anything between visits. It would be helpful if they were proactive about contacting me to keep in general touch, rather than putting the ball in my court."*

### **Helping with visits**

Although you want to respect your resident's privacy when they have visitors, dementia can make visits especially fraught. The carer will appreciate your tactful support in negotiating visits. You can give them information about what the resident has been doing, and join in a three-way conversation to help ease the start of the visit. Offering refreshments, and helping move the person with dementia to a comfortable place, will help the carer feel at home. At the end of the visit, work with the carer to help them leave, especially if there is a risk the resident will become very upset. Carers can also be distressed on leaving, so check they are alright before they go.

*Carer's perspective: "Mum tends to think she is in a hotel. 'Home' to her means the home of her childhood. Sometimes she thinks I am her mother; she may be fretting that she has not heard from her parents, who are long dead. I find it very difficult to know what to say to her when I see her and how to play the visits, as it depends on reading her moods and her concept of reality on each occasion. Everything about our shared life (and my real life) is liable to disturb her understanding of her surroundings. As a carer you have an emotional investment in each visit, aware it could be the last, or that the person may have declined by next time."*



### Welcoming feedback and encouraging discussion

Many carers are nervous about voicing concerns, because they do not want to alienate staff. It is important to set the right tone in relationships with carers, helping them feel comfortable about saying what they think by making time and space for genuine conversations. It may seem that some carers can be critical, but this is often an expression of their concern and anxiety over their relative with dementia.

### Providing respite care

Your care home may also be providing a respite service for carers of people with dementia. Many of the principles above apply equally to these short placements, but there is likely to be intense anxiety for the carer who may not previously have left their person with dementia overnight. Providing reassurance, and inviting 'phone calls to check how the person is settling, will give the carer peace of mind. So that the person with dementia is not too unsettled by being away from home try to stick to the routines the carer has at home.

### Giving end of life care

Working with a person in the later stages of dementia, you have the privilege of supporting them at the end of their life. Liaising closely with the carer is essential in providing compassionate care. Preparation for these final days begins even before the person with dementia is admitted, and the process of planning end of life care continues throughout their time living in the home. You need particular tact and sensitivity in discussing this aspect of care with families.

Carer's perspective: "In the last months of my husband's life, he was very frail and weak after a serious illness. The staff felt he needed to spend every alternate day in his room, to give him enough rest and quiet. I agreed, but I wanted him to have some degree of pleasurable interest and social interaction. I asked if he could go to the Sabbath service in the care home's synagogue and also to the Thursday film session. They readily saw my point of view and agreed. Some days he would be taken to the dining room and we would give him lunch at his usual table by the window. I feel this sensitive, co-operative approach in his final days illustrated the best kind of responsive care."

### Key tips for residential care workers

- Be aware of the difficult feelings carers experience on their relative or friend's admission to care.
- Find ways to work in partnership by valuing the carer's expertise.
- Encourage the carer to provide life story information.
- Keep the carer in the picture by giving regular updates.
- Make the carer feel welcome when they visit.
- Embrace feedback on how you might do better.
- Communicate in the staff team so conversations with carers are not lost.

## 8 Social workers, care managers & self-directed support practitioners

Carer's perspective: "My main problem was my mum's lack of awareness of her condition and resistance to acknowledge she needed help. The referral to the social worker was a turning point. She visited Mum alongside the health visitor and played it sensitively and tactfully. As I live 100 miles away from mum, I was never able to meet [the social worker] in person, but she said I was welcome to call or email her at any time. Several times she spoke to me on the phone for about an hour. Of all the professionals, I felt she had the most insight into behaviour in dementia. It was she who told me that I needed to be looking at residential care, as Mum was getting to the point where she was not safe to be at home alone. I knew this myself, but was in huge emotional turmoil and felt paralysed by this."

Social workers, care managers and self-directed support practitioners all have unique support roles for people with dementia and their carers. Some suggestions and perspectives from carers to support partnership working are given here.

### Feeling your way into the situation

Tact and diplomacy are more vital than ever when visiting families where dementia is the cause of care needs. Whereas in other caring relationships the person receiving care accepts they have needs, with dementia it is hard to explain to the person why social services are involved; people with dementia often lack the insight and cognitive ability to grasp the impact of their changing needs on family members. Spending time listening and observing will help you gain a feel for what is happening in the home and where the pressures points lie. This includes hearing the perspective of the person with dementia and involving them in all conversations about their care, but it may also entail picking up the slightly different messages the carer wants to give about how they are managing and coping.

Carer's perspective: "Mum needs help with everything. I visit to bring her food, fill the fridge, do the washing, clean the house, but she told the care manager that she does everything. The care manager looked in the fridge, found it full, and concluded she did not need any help. If the care manager had told me when she was visiting, I would have been there to explain how things really are."

### Being knowledgeable about dementia and services that can help

Carer's perspective: "The most important thing for social workers is the ability to listen and then explain things clearly. I found it really confusing to be given different advice about the notice period when asking for respite provision. It varied between three weeks and eight weeks, depending on who I spoke to. It was extremely stressful on one occasion when I gave six weeks' notice and a care home was only found a week before, allowing little time to visit and feel confident in making the decision."

After a diagnosis, families often decide they can manage without help. It takes time to reach the point when needs have increased and the carer can accept help; even then it may feel like failure, or a broken promise. Carers struggle to recognise they have this role, 'carer', and as a professional you can help them work through what it means and recognise there is no shame in admitting you are struggling.

In order to give the best possible help and advice to support people with dementia, carers suggest that knowledge and skills in two key areas are vital:

- Understanding dementia – understanding grows through experience, but it will also be important to keep your knowledge up-to-date in the usual ways. Ideas about best practice are developing constantly and ongoing research refreshes our ideas about what will help.
- Understanding the role of benefits and services – by keeping in touch with provision in your area by networking and by visiting local services, you will be well placed to make suggestions that match the need at each stage in the dementia journey. The carer will rely on you to give accurate, up-to-date information. It may be worth attending courses on legal and financial matters relevant to working with people with dementia.

Being introduced to the world of social care can be bewildering and you can help by using clear explanations and plain English to describe sources of help. Some carers prefer concrete examples of support available, others find it helpful being asked general questions about 'What would help you?' A short tailored list of organisations may be appreciated by a carer who is feeling bewildered by the sheer volume of information available.

### Using a problem-solving approach

You may find yourself employing new tactics for introducing support if the person with dementia cannot accept they have needs, and that their carer needs support. Conventional approaches may meet with resistance, so introducing new people slowly and building support gradually may be necessary. You might have to work with the person with dementia, helping them understand their carer needs a rest, before they agree to try out a new day centre, for example.

Another aspect of supporting families of people with dementia is that the situation rarely stays the same for more than a few weeks. Dementia is progressive, so you will need to explain to the carer how to keep social services informed of changes so that support going in to the home is adjusted regularly. Carers feel anxious when they are discharged after support packages are put in place, unsure who to contact in a crisis. need to know who to contact if they have a problem with any of the agencies supporting them, and to feel sure that the problem will be resolved quickly.

*Carer's perspective: "When the care manager sets up support from a care agency, there must be a constant flow of communication, and prompt actions when changes are needed. When there was a dispute or non availability of care services from the agency, I wanted the care manager not to be biased but to look at the facts of the matter and respond fairly and not in favour of the care agency."*

### Helping the carer see their needs

The needs of the person with dementia tend to be the focus of everyone involved with a family, from friends and relatives to health and social care professionals. The spotlight is rarely on the carer, and how their life has changed. One of the key ways you can support carers is by helping them see the needs they have too, and encouraging them to accept help. This involves acknowledging and valuing their central role in supporting the person with dementia, and accepting them as the expert in their care. It also means avoiding value judgements about the carer's choices, such as any suggestion that they could be doing more. By showing you respect the carer's right to have their own life – at work and in relationships, for example – you help them accept their needs are legitimate.

Carers of people with dementia have made some practical suggestions for working in ways that support the carer:

- Helping in the difficult decisions. Carers of people with dementia agonise over decisions they have to make on behalf of the person who lacks capacity. It helps if the social worker can confirm when the time is approaching to take the next steps in the dementia pathway.
- Assessing separately. If you carry out the carer assessment at the same time as the assessment of the person with dementia, the carer may scarcely realise that they are the focus. Assessing their needs at a different time, if possible when the person with dementia is not present, will help them say honestly how they are coping.
- Offering personal budgets. Having control of how the budget for supporting the person with dementia is spent can transform the experience for carers facing resistance from a relative who lacks insight. It enables more flexible responses and can be actively promoted to carers of people with dementia.

- Making the contacts for the carer. Carers are often tired and sceptical, so may not get round to 'phoning the organisation you suggested as a source of help. Can you help by establishing the contact for them?
- Advocating on behalf of the carer. Your role might include speaking up for the carer to ensure they receive help to which they are entitled.

Carer's perspective: "Our social worker had failed to attend two previously-scheduled appointments, yet did not apologise for this. When she did attend, she insisted on asking for financial information before discussing anything else. Her attitude was very negative; she had lots to say about the help we couldn't have, but little to say about what was possible. I was so annoyed that I said we could manage without help. It was another two years before my daughter persuaded me to try again. The next social worker was excellent. She arranged day care and respite. What a difference!"

### Approved mental health professional (AMHP) roles

Some roles in relation to people with dementia are exclusively reserved for social workers who are AMHPs. If you are working with this client group, you will require training and support in implementing protocol and local procedures in these specialist areas in particular their behalf are in their best interests. It is important to note that suitably trained and warranted nurses, psychologists and occupational therapist can also AMHPs.

### The law and dementia

The Mental Capacity Act 2005 gives clear guidance on supporting people who may lack capacity as a result of conditions such as dementia. You may be involved in assessing the person's ability to consent to care; if they are assessed as unable to consent, you will be involved in ensuring decisions made on their behalf are in their best interests. You may also be involved in Deprivation of Liberty Safeguards, which were attached to the Mental Capacity Act in 2007, but you would need to be qualified as a Best Interests Assessor - BIA). On rare occasions people with dementia are sectioned under the Mental Health Act for their own safety (see Mental Health Act 1983 and Mental Health Act 2007).

### Safeguarding

As 'adults at risk', people with dementia fall under the responsibility of local safeguarding adults boards. Social services departments are the lead organisations in taking forward allegations of abuse of adults at risk and need to ensure local procedures are met. It is worth thinking through and understanding ways in which people with dementia are at risk and what might be indicators that they have been victims of abuse.

### Key tips for social workers

- Sum up relationships in a family and respond sensitively.
- Understand how the person with dementia sees their world.
- Be an expert on local dementia services.
- Be prepared to work creatively and flexibly in sourcing help.
- Be an ally and an advocate for the carer in making decisions.
- Put the spotlight on the carer and help them be kind to themselves.
- Understand the law around dementia.

## 9 Social care managers in provider settings

Managers in many different social care settings are responsible for identifying and responding to the needs of carers of people with dementia. Their way of working sets the culture for the service they provide.

Carer's perspective: "The carers' support service had an excellent manager. He arranged for someone to go in on a Saturday evening to sit with the person with dementia, so the carer could attend a special function. Another manager in the same organisation encouraged staff to visit the carer for a while after the person with dementia had gone into residential care."

### Leading by example

Carers of people with dementia like to see managers taking an active, hands-on role, not staying in their office but having regular contact with the people they help and observing any changes in individual people using the service. In this way they can be role models for good communication, not just with people with dementia, but also with their family members. If they demonstrate respect and a desire to work in partnership with carers, staff will also adopt this approach.

Carer's perspective: "They said Mum could no longer go to the day care because she was not benefitting anymore. This was the only break I got. The manager only gave me a week's notice, just called me to a meeting and dropped the bombshell. I said this was the one thing that keeps me going and she replied they were not 'babysitters'."

### Supporting and training staff

Carers understand the pressures faced by staff on the frontline of providing dementia care. They place a high value on staff training and development, seeing how it supports high quality care. Training sessions provide space for staff to consider the pressures dementia places on families, giving them time to understand emotional responses from relatives and showing them ways to respond sensitively, rather than being over-sensitive when anger or frustration is expressed. Good supervision and opportunities for team reflection also help staff develop skill in working with carers.

### Keeping up-to-date and supporting staff to implement new ideas

The field of dementia care is fast-moving and ideas about best practice change. Managers who support staff in introducing new ways of working will achieve better outcomes for people with dementia and their carers. How are you facilitating the implementation of best practice into your service?

### Welcoming suggestions

Carers bring a valuable outsider's perspective on your service. Their knowledge of dementia, combined with their desire to achieve the best outcomes for their relative, make their views an ideal resource in planning improvements. This can involve being open in your responses to individual carers. It may also involve providing regular, structured opportunities for carers to give their views. This could be via postal questionnaires, telephone surveys, or meetings where feedback is invited.

Seeing tangible ways you have acted on their suggestions will give carers faith in the process.

Carer's perspective: "I felt the home manager should listen to my perspective as a family carer, and heed my constructive criticism of the care given to my wife during respite visits. They should lead by example, with hands on involvement, and convince staff to respond to carers' concerns promptly and fairly."

### Being efficient

Leading well means being organised, thinking ahead and having good systems. Keeping carers informed and involved is essential when supporting people with dementia, and will require careful planning and excellent communication. If there are changes in the way the service is run, carers need to be informed as soon as possible. You can delegate these tasks to team leaders, but check they are keeping up with the responsibilities. A simple thing, like replying quickly to emails and other communication, gives the carer confidence and minimises the likelihood of frustration. Being proactive in involving relatives also reduces the risk of problems escalating and resulting in a formal complaint.

Carer's perspective: "The manager of my mum's care home is always on the ball and responds quickly to any queries. When I emailed her about a blocked toilet in Mum's room, she responded immediately and had maintenance deal with it as a priority. She wrote to families recently to explain a fee raise, in a way I felt was clear and responsible. And she seems to take care of staff welfare and morale, so you generally feel that it is a happy place for them to work and for the residents to live. This, I think, is down to firm, clear leadership and good communication."

### Key tips for social care managers in provider settings

- Be a role model for staff in communicating well with carers.
- Support staff and ensure they are well trained.
- Keep up-to-date with best practice in dementia care.
- Network with other managers of dementia care services.
- Be open to comments and criticisms from carers and act on them.
- Develop good systems for involving and communicating with carers.
- Give regular updates about the service and staffing matters.

## 10 Conclusion

A carer's perspective reported: Edna refused to let the domiciliary care worker do anything for her, and it was getting to be a real problem for her husband who desperately needed support. So the care manager thought long and hard about what might be causing this problem. She wondered if Edna might be thinking something was going on between the domiciliary care worker and her husband and suggested that when the worker came, the husband took the opportunity to go out and buy his newspaper. This worked a treat—Iris was pleasant and obliging with the care worker when her husband was not there. It took imagination and empathy to solve the problem.

Some key suggestions as to how you can work more effectively with the carers of people with dementia:

### **Think yourself into the carer's situation**

Think how life would change if someone close to you developed dementia. Understand how the carer must feel when they can no longer carry on with the life they had been used to. Each time you have contact with the carer, imagine what might have happened already that day to contribute to stress and tiredness, and remember to ask how they are.

### **Be positive and imaginative when thinking about providing support**

Try not to say that something the carer suggests or requests is not possible, but figure out ways you could make it work for the family. Be creative and adopt a problem-solving approach to help overcome obstacles by offering original and individual responses. Be optimistic, not focusing on the negatives but seizing the potential for wellbeing in dementia and encouraging the carer to hold on to roles and relationships which maintain their own identity.

### **Treat the carer and the person with dementia with friendship, dignity and respect**

Always remember that it is what you bring as a person to the relationship with the family that makes the biggest contribution. Building mutual respect, warmth and concern into your dealings with the family will ensure that you become a key part of the team who are supporting the person with dementia. The person with dementia will sense if you enjoy being with them, and will relax in your company, which in turn will help the carer to feel confident.

Carer's perspective: A support worker who worked with my mother was remarkable. She was a young, and despite my mother's best attempts to get rid of her, stuck it out for four hours each week. She volunteered to give her lunch, even though that was not in her remit. She kept to the day and time agreed and called her 'Mum', as she knew that, being from the Caribbean, this would build my mum's trust. She even visited her when I was away and Mum was in respite care. After she finished working with us, she kept in touch, attending my mother's 90th birthday party while she was in a step-down placement from hospital."



## 11 Further reading from Skills for Care

This is one of four related publications all free from the 'Developing skills' > 'Dementia' page of [www.skillsforcare.org.uk](http://www.skillsforcare.org.uk) The others are:

- *Common Core Principles for Supporting People with Dementia*
- *Supporting Dementia Workers*
- *Resources for dementia care*

See also the Dementia UK site, [www.dementiauk.org](http://www.dementiauk.org)



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© Skills for Care 2012

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