
Dementia & carers: workers' resources

Information for care workers supporting family and friends carers of people with dementia

Spring 2012

“we help care workers develop partnership working”



in partnership with
Dementia UK
Improving quality of life



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 brief resource guide and a fuller guide called *Dementia: workers & carers together*.

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

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



Sharon Allen
Chief Executive Officer
Skills for Care



Barbara Stephens
Chief Executive
Dementia UK

Dementia & carers: workers' resources. Information for care workers supporting family and friends carers of people with dementia

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

Dementia UK, 6 Camden High Ro, London NW1 0DH www.dementiauk.org

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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.

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1 About this guide

This guide is designed to support social care staff who are working with the carers of people with dementia.

It provides useful, succinct and accessible information for the workforce to use in their day to day roles with carers and people with dementia. It is designed to be used in conjunction with *Dementia: workers and carers together*.

The guide contains information regarding dementia as a disease, support available for carers, signposting to further help as well as other useful information for workers to share with carers.

A note on the word 'carer'. This guide 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.

2 Helping carers recognise signs and symptoms of dementia, and supporting them when there is a diagnosis

You may be working with carers of people with other illnesses or disabilities who may be concerned their loved ones are showing signs and symptoms of dementia, or you may notice things that you are concerned about.

Key things that you may need know & that you may need to support carers with:

- Only 40% of people of people with dementia ever receive a medical diagnosis—carers and people with dementia should be supported to seek a diagnosis if dementia is suspected.
- Dementia can have symptoms in common with other illnesses, making medical diagnosis even more important.
- Dementia is a progressive illness—signs and symptoms will get worse over time and the support you need to provide to the carer may alter over time. However, there are many things that can be done to support people with dementia to live well with dementia—you can reassure carers on this and be aware of things that may help.

Understanding the signs and symptoms of dementia

In your role, you can support carers of people with dementia by being aware of what the early signs and symptoms are:

- loss or lapses of recent memory
- mood changes or uncharacteristic behaviour (in later stages this will become more pronounced)
- poor concentration
- problems communicating
- getting lost in familiar places
- making mistakes in a previously learned skill (e.g. cookery)
- problems telling the time or using money
- changes in sleep patterns and appetite
- personality changes
- visio-spatial perception issues (i.e. the brain does not process images as normal).

Seeking a diagnosis

You can also support the person with dementia (and their carer) to obtain a diagnosis. The person with dementia and their carer will be very anxious during this process so will need support. Obtaining a diagnosis for suspected dementia is similar to obtaining diagnosis for other illnesses and diseases.

The first stage is to seek an appointment with a General Practitioner (GP). If the GP is concerned by the symptoms, and has ruled out any other potential causes of some of the issues above, then a referral will be made to a specialist dementia or memory clinic. If people with dementia and carers are still concerned, they can insist on a referral—you can advise them of this.

Once referred, further assessments, tests and scans will take place and a diagnosis may or may not be given. If a confirmed diagnosis is received, this will be very difficult and emotionally stressful for both the person with dementia and their carer and both will need your support.

Brief information about treatments for dementia

Medical treatments for early to mid-stages of dementia

Unfortunately, there are no drugs that can cure dementia; however, there are some drugs available that can slow the progression of the disease, or temporarily improve the symptoms. In addition, there are other drugs that can support the treatment of some of the symptoms such as depression or anxiety. GPs or consultants will advise on the use of drugs and prescribe them if required.

Non-medical treatments

There are a number of recognised non-medical treatments for dementia, these include:

- social interaction with family and friends
- reminiscence therapy such as life story activity
- treating pain that may be causing agitation
- aromatherapy
- animal therapy
- music and dance therapy
- massage
- exercise and physical activity.

3 Supporting carers to prepare for the later stages of dementia

As the symptoms of the dementia progress, things will become more challenging for the person with dementia and their carer. Working alongside carers, there are things that you can advise and do, to support them.

Key things that you may need know & that you may need to support carers with:

- The signs and symptoms highlighted in section 2 will progress and become more severe.
- It is likely that puzzling behaviour that the carer may find challenging will increase, including aggression—you need to think of ways to support the carer to manage this, particularly if the person with dementia is still living at home.
- You should be aware of anti-psychotic drugs and situations when they are likely to be prescribed for short period by a doctor.
- You will need to have an awareness of the different aspects of health and social care services that can support people with dementia (see following sections).

Managing behaviour that you and carers may find challenging

You can support carers to manage behaviour we may all find challenging, such as aggression.

The following approach is suggested by the Alzheimer's Society if an episode of aggression occurs:

- 1 Find ways to react calmly if challenging behaviour has occurred
- 2 Work out what triggers the aggressive behaviour
- 3 Tackle the triggers
- 4 Take time to manage your own feelings
- 5 Be creative in finding alternative activities to help an individual move on from feelings of anxiety.

Anti-psychotic drugs

Anti-psychotic drugs can be prescribed for behavioural and psychological symptoms in the later stages of dementia for a **short period of up to 12 weeks**. It is important that carers are aware of this, and they should also be aware that while anti-psychotic drugs can address more significant psychological symptoms such as psychosis and aggressive behaviour, they can also have negative side effects. National Institute of Clinical Excellence (NICE guidance) suggests that anti-psychotic drugs should not be used for early to middle stages of dementia and that non-medical interventions should be used instead (see list in section 2 above).

4 Types of care and support for people with dementia and their carers

There are a number of care and other support services available to support people with dementia and their carers. Some will be familiar, others less so, but it is important that you are aware of the services and are able to discuss them with people with dementia and their carers.

Key things that you may need know & that you may need to support carers with:

- Short term support options
- Long term support options
- Information and advice services

Accessing support

People diagnosed with dementia are entitled to an assessment by the local authority to assess their needs and to determine the services they are entitled to. Entitlement is based on level of need, and is also means tested. In addition to this, *the carer* is also entitled to an assessment to identify their own needs. If the means testing leads to support not being funded by the local authority, then self-funded care can be considered.

Short term support options

Respite care allows a break for carers from their caring responsibilities and support for the person with dementia in a residential care home for up to several nights. As well as providing a break for the carer, this option also provides an opportunity to pursue aspects in their life that may have become more difficult since their loved one developed dementia, for example catching up with close friends.

Day care provides a support service for the person with dementia during the day. This will involve the person with the day centre with (see the section on day care in *Dementia: workers and carers together*).

Many communities have dementia friendly services that people with dementia and their carers are able to enjoy, such as dementia

cafes, community groups and other dementia-friendly services. They provide opportunities to meet other people in similar circumstances. With the increasing awareness of dementia, it is likely that more and more services will become dementia-friendly.

Long-term support options

Domiciliary care is an option for people with dementia who are still living in their own home. The services are provided by a domiciliary care agency and involve a domiciliary care worker going into the home to support the person with dementia and their carer (see the section on domiciliary care workers in *Dementia: workers and carers together*).

Personal assistants can be employed by carers or people with dementia to work closely with the person with dementia to support them with everyday activities (see the section on PAs in *Dementia: workers and carers together*).

Residential care with or without nursing is an option for people in the later stages of dementia where it has become difficult to care for them at home (see the section on residential care in *Dementia: workers and carers together*).

See the Resources page for details of information and advice services.

5 Things to help carers support someone to live well with dementia in their own home, including assistive technologies

A number of things can be done to support people with dementia to continue to live in their own homes. This will also assist carers in their longer term care and support role. It is important that you are aware of the possibilities and are able to discuss them with people with dementia and their carers.

Key things that you may need know & that you may need to support carers with:

- Support staff who may be able to help you when you are working with carers and people with dementia.
- Support options that are available for people with dementia and being able to discuss these options with carers.
- Assistive technology that is available for people with dementia and being able to discuss these options with carers.

Support staff who can help

The local authority or local NHS services will be able to highlight how to access other professionals who will be able to help to support people with dementia. The professionals who will be able to help include occupational therapists, physiotherapists, district nurses and continence advisors. In addition to this Admiral Nurses (see Resources page) will be able to provide support and advice to carers in the later stages of dementia,

Assistive technology support options

Assistive technologies include 'high-tech' electronic and telecommunications equipment and services, as well as 'low-tech' mechanical devices. They can support people with dementia to be safe or carry out everyday activities.

The types of support equipment available include: memory aids, equipment for washing and for using the toilet, equipment for maintaining continence and personal dignity, equipment for eating and drinking, mobility aids, cooking aids, transfer aids and adaptations to seating and beds. At the more high-tech end of the spectrum are telecare safety devices, medication devices, memory aids, and location devices.

Supporting dignity and independence

The options identified above are ways that support people with dementia to live as independently as possible, and with dignity. They can also support carers, by helping assure them that their loved one is safe, as well as being independent.

6 Support for carers of people with dementia, including carer's assessments

A number of things can be done to support carers in addition to your existing role in whichever capacity you are working with them. Caring for someone who has dementia can be very challenging for their loved ones, particularly in the later stages of the disease. It is vital that carers receive the support they need to safeguard their physical and mental wellbeing, which in turn has a positive impact on the person with dementia. The different parts of the social care workforce can contribute to this in different ways.

Key things that you may need know & that you may need to support carers with:

- It is important to ensure carers receive some time for themselves—this is helped by supporting the person with dementia to access services such as day care or respite care.
- Carers need to be reassured that their loved ones will be safe when they are not caring for them.
- It maybe helpful to encourage carers to access local networks for support. Could a friend sit with the person with dementia while the carer goes to the shops or takes part in a leisure activity?
- If the situation seems difficult for the carer (e.g. they are not sleeping), a supportive conversation may identify some solutions to the issues, or just reassure the carer that they are not alone and that there are things that can be done to help.
- The role of General Practitioners (GPs) is critical to ensure the wellbeing of carers, and carers should be supported to seek GP advice if this is required. This may involve someone temporarily caring for the person with dementia.

Helping carers to get support

The types of support that carers need will vary, from time off from their caring responsibilities to being able to access information and advice, and from being able to discuss feelings and concerns with health and social care workers, to counselling if they are suffering from poor mental health.

People working with carers need to ensure carers are trying to meet their own needs as well as those of the person with dementia.

Support from local services

Carers are entitled to a carer's assessment from the local authority. Services they provide to a person with dementia and their carer will be means tested; however, local authorities will certainly be able to advise on a range of appropriate support services.

Carers need to be supported to prepare for the carer's assessment. They need to think through key questions, such as how they are managing and what support they may need to continue.

Support from family and friends

Support from family and friends for both the person with dementia and their carer is critical. This could be support in meeting care needs, or contributing to the costs of care. Carers may need to be supported to ask for help, as well being supported to accept any help that is offered. Family and friends may also need support with meeting the care needs of somebody with dementia. The *Common Core Principles for Supporting People with Dementia* contain clear and concise practical information which can be used to support friends and family to take on caring responsibilities for a person with dementia in a person-centred way.

7 Legal issues for carers and people with dementia

The legal considerations relating to a person with dementia are numerous and complex. Below follows a brief overview of some key legislation that people working in social care will need to be aware of when working with people with dementia and their carers.

Skills for Care and Dementia UK accept no responsibility for the legal accuracy, interpretation or use of the information below. It also should be noted that this is not an exhaustive list as there is other legislation that may be relevant to people with dementia. If specific legal advice is needed by people with dementia or their carers, or people working to support them, then the Citizens Advice Bureau or local legal services will be able to offer advice.

Key things that you may need know & that you may need to support carers with:

- The relevant legislation applicable to people with dementia, particularly in the later stages of the disease.
- Brief understanding of Lasting Power of Attorney and how this applies to people with dementia and the role that carers can play as an 'attorney' in the later stages of dementia.
- Understanding of the Deprivation of Liberty Safeguards.

Legislation and its relevance to a person with dementia and their carer

The Mental Health Act 1983

The Mental Health Act ensures the rights of people with mental illness—this includes dementia.

If a health professional (usually a doctor) thinks that a person with dementia is behaving in a way that places their health at risk or is a danger to themselves or others, this Act allows the person to be detained in hospital ('sectioned').

The Act also allows for individuals to be appointed to make decisions on behalf of people with a mental disorder. These individuals (known as guardians) can require that a person lives in a certain place, has access to health professionals and attends appointments relating to their care and treatment.

Mental Capacity Act 2005

The Mental Capacity Act 2005 makes provision for people to choose someone to manage their finances and property should they become incapable, and to make health and welfare

decisions on their behalf. Again, this Act applies to people with dementia.

Lasting (formerly 'enduring') Power of Attorney

People with dementia who lack the mental capacity to manage their legal, financial and health affairs are able to choose someone to manage these under a Lasting Power of Attorney. Lasting Power of Attorney occurs in two types: property and affairs and personal welfare. The powers can be used only when the attorney has been registered at the Office of the Public Guardian (OPG). The attorney is often the person's main carer.

Deprivation of Liberty Safeguards (DoLS)

The DoLS are part of the Mental Capacity Act 2005. They protect people in care services and hospitals from being inappropriately deprived of their liberty. The safeguards aim to make sure that a care home or hospital restricts the person's liberty only safely and correctly, and that this is done only when there is no other way to take care of that person safely. The DoLS are most likely to be relevant in the later stages of dementia.

8 Financial issues for carers and people with dementia

Financial matters will be of significant concern for people with dementia and their carers. With both likely to have to give up work in the later stages of dementia, it is vital that people working with carers understand the key financial considerations for people with dementia and carers so they are able to support them appropriately.

Skills for Care and Dementia UK accept no responsibility for the interpretation and use of the information below. If specific financial advice is needed by people with dementia or their carers, or people working to support them, then the Citizens Advice Bureau, benefits advice line, local authority or local legal or financial services will be able to offer advice.

Key things that you may need know & that you may need to support carers with:

- Understanding of any benefits and council tax discount to which people with dementia and their carers maybe entitled.
- Employment regulations about carers who are still working.
- Paying for the costs of care and support.

Understanding of any benefits and council tax discount to which people with dementia and their carers maybe entitled

People with dementia and their carers may be entitled to a number of different benefits. The most appropriate thing to do is to initially contact the benefits helpline on 0800 882 200 for further advice.

Alternatively, the Directgov website provides further information:
www.direct.gov.uk/en/index.htm

Carers who are still working

Carers are entitled to request flexible working arrangements to meet their care needs. Combined with the right care and support package, this may enable the carer to remain in work.

Paying for the costs of care and support

See section 4 above.

9 Resources and information

Useful websites

Dementia UK www.dementiauk.org

See in particular contact points for Admiral Nurses and for 'uniting carers'.

Skills for Care www.skillsforcare.org.uk

See in particular the 'Developing skills' section for pages on dementia (including the *Common Core Principles for Supporting People with Dementia*) and on *Carers Matter, Everybody's Business*.

Alzheimer's Society www.alzheimers.org.uk

See also the Alzheimer's Society **Talking Point** online forum moderated by people who have been affected by dementia in some way:
<http://forum.alzheimers.org.uk/forum.php>

Carers UK

www.carersuk.org

Citizens Advice Bureau

www.citizensadvice.org.uk

Information and advice helplines

Dementia UK's Admiral Nursing Direct is on 0845 257 9406

The Alzheimer's Society helpline to support people with dementia and their carers: 0845 300 0336

Carers UK advice line specifically to support carers: 0808 808 7777

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

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

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Dementia UK
6 Camden High Street
London
NW1 0JH

telephone 020 7874 7200
fax 0845 519 2560
email info@dementiauk.org
web www.dementiauk.org

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