

Dementia handbook for carers

Berkshire West

About this handbook

What is dementia?

Medication and treatment

Day-to-day living

Planning ahead 1	Everyday activities 18
Being a carer 2	Getting out and about 20
Family dynamics 5	Caring for physical health 24
Adaptations at home 8	Hospital visits and stays 27
Adaptations for behaviour 12	Preparing for difficult decisions 29
Tips for reducing stress 16	

Support

Health and Social Services 8	Financial support 13
Local support services 10	Assistive technology 15
Activities 11	Care, quality and safety 16
National organisations 12	

Legal and money matters

Legal issues 1	Money matters 5
-----------------------	------------------------

A-Z of symptoms and behaviours

Dementia look-up guide 1	Glossary 21
---------------------------------	--------------------

Record keeping

- Contacts
- Appointment record
- Questions and concerns
- Summary sheet for medical and care professionals
- Medication record (renewing prescriptions)
- Pain assessment
- Services and support checklist
- Notes and Care Plan

Understanding dementia

Day-to-day living

Support

Legal and money matters

A-Z of symptoms and behaviours

Record keeping

Foreword

There are already around 800,000 people living with dementia in the UK. With rapid population ageing, we expect this figure approximately to double over the next two decades. There is also a national “push” in the government’s Dementia Strategy to provide people with earlier and more accurate diagnosis when they begin to experience symptoms which might indicate dementia.

It is often relatives and carers who notice the symptoms of dementia more than the person themselves. They can experience initial relief that someone has finally taken their concerns for their loved one on-board and has made a diagnosis. But that’s not much use if they are just “left” with the D-word and don’t know where to turn next. Although some drugs can have a modest benefit in some types of dementia, what’s more important is for the person living with dementia and those who support them to get advice and support for the future.

Questions might include:

- what can we expect in the future?
- do we need to adapt our home or even move?
- what’s the right way to support people when their memory is failing or their behaviour changes?
- what if they have to come into hospital?
- do we need to make any written decisions about future medical treatment?
- who can we turn to for support and advice?
- how can we pay for long term care if it’s needed?

Professor David Oliver

BA, MB BChir, DGM, MHM, MD, Dip. Med. Ed, MSc, MA, FRCP

Consultant Physician, Royal Berkshire NHS Foundation Trust

Visiting Professor, City University and Surrey University

Visiting Senior Fellow, the King’s Fund

President-elect, British Geriatrics Society

The Berkshire Healthcare “Dementia handbook for carers” aims to answer these questions and many more with the information based around what services are available locally, in the west of Berkshire. There are sections on Day-to-day living, Support, Legal and money matters, an A–Z of symptoms and behaviours and a section on Record keeping and updating relevant care documents.

We are very grateful for the work led by the Centre for Information Design Research at the University of Reading in preparing this handbook. The research team at the University worked closely with a group of carers for people living with dementia as part of a research project. The work resulted in a handbook co-designed by potential users (i.e. carers) in a format and style that suited their needs. By giving this handbook to those with a new diagnosis of dementia and their carers, we aim to get people off to a positive start with the information they need readily to hand.

I hope it helps to make living with dementia easier and more hopeful for our local community.

Acknowledgements

This handbook has been prepared as a collaboration between Berkshire Healthcare and the Centre for Information Design Research, University of Reading. The research project, led by Dr Luke Solomons, was funded under the Prime Minister's Challenge 2012 initiative by the West Berkshire CCG Confederation.

We would like to thank all the carers who kindly gave their valuable time and experience to contribute to the handbook. And to thank Claire Garley from Alzheimer's Society and Carol Brindley, Marielle Kay and Sylvia Roberts from the West Berkshire Memory Clinics for sharing their knowledge and experience.

We are also grateful to the staff and volunteers from the following organisations who have taken the time to contribute so generously to the handbook's development:

Age Concern Woodley, Alzheimer's Society Reading, Beechcroft Memory Clinic at West Berkshire Community Hospital, Hazelwood Memory Clinic at Prospect Park Hospital, Wokingham Memory Clinic at Barkham Day Hospital, the Older People's Mental Health Liaison Team at Royal Berkshire Hospital.

Questions about this handbook

Email: Vicki.Matthews@berkshire.nhs.uk

For electronic copies of this handbook visit

www.berkshirehealthcare.nhs.uk/dementiahandbook

Produced by:

 **University of Reading** | Centre for Information Design Research

Berkshire Healthcare 
NHS Foundation Trust

Funded by:

 *Newbury and District Clinical Commissioning Group*  *North and West Reading Clinical Commissioning Group*  *South Reading Clinical Commissioning Group*  *Wokingham Clinical Commissioning Group*

About this handbook

You have been given this handbook because you are caring for someone who has a diagnosis of dementia. It aims to summarise the wide range of things you and the person you are caring for may need to consider in planning for the future.

Some of the information in this handbook will be important now. Other information will be useful later. The aim is for you to keep this handbook to refer to when you need it.

Dementia is a general term for a wide range of conditions. This includes Alzheimer's disease, Vascular dementia, Fronto-temporal dementia, Dementia with Lewy bodies, and other types of dementia. These conditions can have different symptoms and may need different kinds of treatment. Since this is a general guide for all dementias, it's worth remembering that not everything in the handbook will be relevant to the person you are caring for.

What is in the handbook

This handbook contains the following sections:

What is dementia?

- a brief guide to the different types of dementia and typical symptoms, with a summary of the medication and treatments that may be used to help people with dementia.

Day-to-day living

- describes how families can support a person with dementia, help them **get the most out of life** and stay comfortable at home
- suggests ways to **adapt everyday life** to a person's changing symptoms and behaviour.

Legal and money matters

- covers the important **legal issues** that affect someone with dementia and the plans that can be put in place to make sure they are protected for the future
- describes the **benefits and help** that may be available to fund the care a person needs.

Support

- a chart of the different **sources of medical and care support** for people with dementia and their carers
- contact details for **local support and services**.

A–Z of symptoms and behaviours

- **symptoms and changes in behaviour** that people with dementia may experience, with tips for how to help the person you care for feel more comfortable
- a **glossary of abbreviations** and medical terms that are commonly used in the care of people with dementia.

Record keeping

- a section **for you to make notes** of important contacts, to log records of things you might want to discuss with your GP or other professionals who are supporting you, and to store details of appointments and letters.

How to get the most from the handbook

The handbook is intended to cover a wide range of issues that you may need to consider. It will not give you every detail you need. However, it does include pointers to more detailed sources of information.

Add information to your handbook

The handbook is a loose-leaf binder so that you can add more information that is helpful to you. For example, the Memory Clinic may give you more detailed information about the type of dementia that has been diagnosed; or you may want to add notes from a carers' course you have attended, or a list of current medication and a copy of the Care Plan within "Record Keeping". The aim is to help you keep the information you need together in one place, so that it's easy to find.

Record keeping

The record keeping section of the handbook is another area where you can make additions to ensure the information you need is easily available. This will be useful if you are talking with a professional about the care a person is receiving and need to refer to the medicines they are taking, letters from doctors they have seen or notes of appointments. Keeping an up-to-date list of the medicines someone is taking is particularly helpful if you are seeing different care professionals.

Share with family and friends

A further benefit of having this information together and easily available is that you will be able to show it to other people, such as your family or close friends. They may also need information to understand what is happening to the person you are caring for and to see how they can help.

Electronic versions of this handbook are available at www.berkshirehealthcare.nhs.uk/dementiahandbook. Go to this address for a pdf version of the handbook and for additional record keeping pages.

Guide to symbols

Throughout the handbook the following symbols are used to highlight certain information that you may find useful.



Tips for things you can try that may improve the person's comfort.



Signposts to further information, some of which is available on the web, or in printed leaflets, or from local or national organisations that support people with dementia and their carers.

What is dementia?

Dementia is the name for several conditions that lead to the progressive loss of the powers of the brain and changes in a person's behaviour. The most common change is in a person's memory, but not everyone has memory problems. Some people with dementia have problems with communication, decision-making or everyday tasks.

Types of dementia

Alzheimer's disease is the most common form of dementia. Vascular dementia is also common.

There are many other types including:

- Mixed dementia
- Fronto-temporal dementia (Pick's disease)
- Dementia with Lewy bodies
- Parkinson's disease dementia
- Normal pressure hydrocephalus
- Huntington's disease.

Some people have memory problems but they are not severe enough to be called "dementia" and may not lead to dementia. This is described as "Mild cognitive impairment".

Sometimes people have more than one type of dementia, usually Alzheimer's and Vascular dementia, and this is called "Mixed dementia".

Dementia is a condition that can occur at any age but is most common in older adults (over 65). Dementia in younger adults (under 65) is often called "Early onset dementia".

Alzheimer's disease

Alzheimer's disease was first described by a German doctor named Alois Alzheimer. The disease causes "plaques and tangles" to develop in the structure of the brain. These block the normal chemicals that send messages around the brain. This causes brain cells to die and eventually results in the volume of the brain shrinking.

Vascular dementia

Vascular dementia is caused by problems with blood circulation in parts of the brain which do not receive enough blood and oxygen, resulting in the death of brain cells.

There are many types of Vascular dementia, including stroke-related and small vessel disease related dementia. Another type is a mixture of the two.

Stroke-related dementia (sometimes called post stroke dementia) Strokes damage the brain by blocking the blood supply to a specific part of the brain. The symptoms depend on where the brain has been damaged. A person may experience weakness or paralysis on one side of the body or have difficulties communicating.

Stroke-related dementia can also be caused by several small strokes in the outer part of the brain called the cortex. These are sometimes called TIAs (transient ischaemic attacks). These can be so small the person may not notice them. However, their effects accumulate so that a person's mental abilities are affected.

Small vessel disease related dementia

Damage to tiny blood vessels that lie deep in the brain can lead to slow development of dementia symptoms.

It can be difficult to separate Alzheimer's disease from Vascular dementia in making a diagnosis. Some people may have both.

Mixed dementia

Mixed dementia is a condition where, most commonly, Alzheimer's disease and Vascular dementia occur at the same time. Many experts believe Mixed dementia occurs more often than was previously realised and that it becomes increasingly common in advanced age.

It is important to recognise if a person has Mixed dementia because the combination of the two diseases may have a greater impact on the brain than either by itself.

Fronto-temporal dementia (Pick's disease)

Fronto-temporal dementia (originally called Pick's disease) covers a range of conditions caused by damage to the frontal or temporal lobes of the brain. These areas of the brain are involved particularly with behaviour, emotional responses and language. People with Fronto-temporal dementia may show early changes in their personality and communication, rather than memory or orientation difficulties, which are more typical of Alzheimer's disease.

Dementia with Lewy bodies

Dementia with Lewy bodies is named after the doctor who discovered it. He found tiny round protein deposits, now known as Lewy bodies, in nerve cells in the brain. Lewy bodies occur in other conditions, including Parkinson's disease dementia.

Dementia with Lewy bodies can have similar symptoms to Alzheimer's disease but people may also experience the following:

- periods of alertness and drowsiness
- fluctuating cognition
- visual hallucinations
- becoming slower in their physical movements.

Parkinson's disease dementia

Sometimes people with Parkinson's disease develop dementia, usually several years after they were first diagnosed. Symptoms are very similar to Dementia with Lewy bodies.

Normal pressure hydrocephalus

Normal pressure hydrocephalus is a brain disorder where excess cerebrospinal fluid accumulates in spaces within the brain (the ventricles), putting pressure on the brain. This could lead to problems with thinking and reasoning, difficulty walking and loss of bladder control.

Huntington's disease

Huntington's disease (HD) is a hereditary, progressive brain condition caused by a defective gene. It causes changes in the central area of the brain, affecting movement, mood and cognition.

Mild cognitive impairment (MCI)

Mild cognitive impairment is not a specific medical condition or disease. It is a general term used to describe a slight but measurable change in the functioning of the brain.

The word “cognitive” is a general term for mental processes, including memory, concentration, speed of thought, ability to use language, organisation and problem solving. MCI can be defined as a deterioration in any of these which is greater than expected for a person’s age, but not severe enough to be classified as dementia.

Dementia in younger people

Most people assume that dementia affects only older people. However, it also currently affects an estimated 18,000 younger people in the UK (between the ages of 40 and 64). They may have similar symptoms to older people but their care may require a different approach because they are likely to be working and have family responsibilities. When their dementia starts, they are likely to be physically more active than older people.

When dementia affects someone under the age of 65, doctors describe it as “early or young onset dementia”, or “working age dementia”.

The most common type of dementia in younger people is Alzheimer’s disease, but others have Vascular dementia, Dementia with Lewy bodies, Fronto-temporal dementia or other rarer types of dementia.

Summary of dementia symptoms

The symptoms people develop vary according to the type of dementia they have. They also differ from person to person. Some people may have just one symptom initially; others may have several symptoms.

Thinking problems

Early symptoms of dementia are often mild and may get worse only very gradually. This means that people with dementia may not notice the signs for some time. Typical symptoms are:

- memory loss, especially memory for recent information, such as messages or names
- difficulties with tasks and activities that require organisation, decision making and planning
- confusion in unfamiliar environments
- difficulty finding the right words
- difficulty with numbers and handling money in shops
- changes in personality and mood.

Some people do not recognise that they have any problems, even when their symptoms are obvious to others. This is called “lack of insight”.

Behaviour changes

The changes resulting from dementia can make people feel anxious, lost, confused and frustrated. They may know something is not right but not be able to grasp what it is. Although each person handles these feelings in their own way, certain reactions to these emotions are common:

- repeating questions or carrying out an activity over and over again

- walking and pacing up and down
- aggression, shouting and screaming
- becoming suspicious of other people
- low mood
- having no concept of time.

Physical changes

Some types of dementia can affect a person’s physical ability:

- poor coordination may make them slow and clumsy when carrying out everyday tasks, such as washing and dressing
- mobility problems may lead to slow movement and walking and, in later stages, loss of ability to walk
- balance problems may put them at risk of falls
- loss of control of their bladder and, in some people, bowel, may lead to incontinence in later stages
- loss of appetite and difficulty swallowing may lead to weight loss.



For more general information including short videos about dementia see www.nhs.uk/Conditions/dementia-guide

Medication and treatment

Currently there is no cure for dementia, but there are drugs and therapies that may help with some symptoms or, in some cases, slow the progression of the disease. The treatment a person will be offered will depend on the type of dementia they have and their symptoms.

Medications will, initially, be prescribed at the Memory Clinic. In time your local GP will probably take over repeat prescriptions.

Medication to relieve or slow down the effects of dementia

For people with Alzheimer's disease, there are currently four drugs available:

- Donepezil (often known by its trade name, Aricept)
- Rivastigmine (trade name, Exelon)
- Galantamine (trade name, Reminyl)
- Memantine (trade name, Ebixa).

These may also be prescribed to people with Mixed dementia with an element of Alzheimer's disease.

The first three drugs in the list above (donepezil, rivastigmine and galantamine) are known as acetylcholinesterase (ACE) inhibitors. They improve communication between brain cells by preventing the breakdown of the chemical messenger acetylcholine. They may be effective for a limited time. Unfortunately they do not work for everyone and sometimes cause side effects such as nausea, vomiting, loss of appetite and diarrhoea; but many people take them without problems.

The fourth medication, memantine, may be prescribed to people with moderate Alzheimer's disease who cannot tolerate any of the three acetylcholinesterase (ACE) inhibitors or to people in the later stages of the condition. Memantine

controls the activity of another chemical messenger, glutamate. It may cause side effects in some people, including dizziness and balance problems, constipation and headaches, but many people have no side effects.

People with Dementia with Lewy bodies or Parkinson's disease dementia might also be offered acetylcholinesterase (ACE) inhibitors as they may help improve some of their symptoms, such as hallucinations.

There are currently no equivalent treatments for Fronto-temporal dementia or Vascular dementia.

Medication to treat underlying conditions

Although there are no treatments for Vascular dementia, GPs may prescribe medication to treat high blood pressure, high cholesterol, heart problems and diabetes. These medications will reduce the risk of strokes which could increase the rate at which Vascular dementia progresses.

People with Vascular dementia may also be given advice about lifestyle changes to reduce risk of strokes, such as stopping smoking, taking exercise and healthy eating.

Medication to relieve specific symptoms

Medication may also be prescribed to help with symptoms such as low mood and anxiety, hallucinations, aggression, agitation and sleep disturbances.

The range of drugs that may be prescribed include:

- antidepressants to treat symptoms of depression, anxiety, agitation or apathy
- sleeping tablets or sedative antidepressants for sleep disturbance
- anticonvulsant drugs to treat symptoms of agitation
- antipsychotic drugs for hallucinations and delusions and sometimes for severe agitation and aggression.

All these medicines can have side effects, so it is important to try non-drug treatments first. If you can find out the cause of a person's symptoms and make changes or give them the right support, they may not need medication. Your Memory Clinic will give you advice to help reduce symptoms without relying on medication.

Antipsychotic medication is often considered only when other options have failed. This is because side effects include sedation, dizziness, muscle stiffness, restlessness and increased risk of strokes.

Medication to relieve pain

Recognising and treating pain is important for a person with dementia as they may not be able to say that they are in pain or understand questions about whether or where they are feeling pain. It may depend on their carer to notice pain symptoms; for example, difficulty sleeping, differences in their mood or behaviour, facial expression or body language. If you think the person you care for is in pain ask for advice from your GP. See "Pain assessment" within "Record keeping".

Treatments at the Memory Clinic

Your Memory Clinic may offer group therapies or individual support that can help the person you care for. Some examples are listed below.

Cognitive Stimulation Therapy (CST)

Cognitive Stimulation Therapy (CST) is a short-term treatment for people with mild to moderate dementia which helps keep their

thought processes and memory active. It is run in groups, which meet once a week for a period of 14 weeks. The groups have a consistent structure with a different "take-home message" each week. The groups provide an opportunity for people to meet others.

Talking Therapies

Talking Therapies give people the opportunity to talk to a trained professional, usually a clinical psychologist or specialist nurse, about problems or issues that are worrying them. They may help people in the earlier stages of dementia to make sense of what is happening to them. Carers may also benefit from talking therapies to talk about their feelings about their caring role. There is a Talking Therapy service across the west of Berkshire, see page 10 of the "Support" booklet.

Carers' course – Understanding Dementia

West Berkshire Memory Clinics run courses for carers to help them understand dementia and to support the person they care for. The courses run for one afternoon or evening over six weeks and cover topics such as memory and communication, physical and behaviour changes in dementia, legal and money matters, and future planning.

Individual consultations

Different professionals from the Memory Clinic team will be able to give advice and support to people with complex needs. The different roles of Memory Clinic professionals are described on page 2 of the "Support" booklet.

Complementary therapies

Complementary therapies are those that are not usually part of conventional medicine but sometimes might be used alongside medical treatments. If the person you care for is taking any herbal medicines (bought from health food shops or some chemists) check with your GP that these are safe for them. It will be useful to list any complementary therapies in the "Medication record" within "Record keeping" so medical staff are aware.

Dementia handbook for carers

Berkshire West

Day-to-day living

Planning ahead **1**

Being a carer **2**

Family dynamics **5**

Adaptations at home **8**

Adaptations for behaviour **12**

Tips for reducing stress **16**

Everyday activities **18**

Getting out and about **20**

Caring for physical health **24**

Hospital visits and stays **27**

Preparing for difficult decisions **29**



Planning ahead

People have different reactions to a diagnosis of dementia. For some it can be a relief to understand why they are having memory problems or other difficulties; for others it can be hard to come to terms with and can cause a lot of anxiety about the future. When someone you care about is given a diagnosis of dementia it is important, for both of you, to try to stay positive and active.

It is still possible to live a full life after a diagnosis of dementia, although you may need to make adaptations for the person, as they need them.

You may want to plan ahead by finding out what support is available for you locally; for example, to make home life easier and safer for the person you care for but also to ensure that you have time to look after yourself as well.

This section discusses the things you can do to stay as positive and supportive as possible.



Being a carer

Nobody asks to become a carer. It may be something you have considered when you have thought about the future, or it may be something you haven't thought about at all. You may need some time to adjust to your new role but your involvement is very important for the person you care for, whether they are living with you, on their own or in a care home.

New responsibilities

A carer can feel overwhelmed by the day-to-day practicalities of supporting someone with dementia, but it is important also to spend time together, share activities, talk about things, such as family or memories of things you have enjoyed in the past. If the person you care for is having difficulties with new environments or experiences, keep the places you go to and the people you see as familiar as you can.

Let your GP know that you are a carer as this will entitle you to certain priorities, for example, a flu vaccination. With time you may become the main source of information about the health of the person you care for. If the person you care for agrees, take them to their GP to sign a consent form for the GP to be able to talk to you about them.

If you spot new symptoms or changes in their behaviour, make a note of them so that, if they

are causing distress, you can discuss them with their GP or a member of your Memory Clinic team. See the sheet "Questions and concerns" in the "Record keeping" section of this handbook for noting down things you want to discuss. If you have friends or relatives who are helping you, share any medical or care advice you receive with them.

You can get support to develop your understanding of dementia and how to care for someone with it from carers' courses run by your Memory Clinic. Contact them to enrol for a course and share the information and advice you receive at the course with other members of the family who are involved.

You can get additional support from voluntary organisations such as your local Alzheimer's Society and Berkshire Carers Service who provide information about both practical and emotional aspects of being a carer.

Memory Clinic

- Reading: 0118 960 5959
- Newbury: 01635 292 070
- Wokingham: 0118 949 5101

Alzheimer's Society

- Reading: 0118 957 1183
- West Berkshire: 01635 500 869
- Wokingham: 01628 626 331

Berkshire Carers Service

- Telephone: 0118 960 7030
www.berkshirecarers.org

For a detailed listing of the different kinds of support available to you see the "Guide to who's who" on page 2 in the "Support" booklet.

There are also legal and financial implications of being a carer, see the booklet "Legal and money matters". It may help to share these responsibilities with other family members, if you can.

Looking after yourself

Many carers are working as well as looking after a relative or friend with dementia. This can be very demanding so it is important that you look after yourself. Even without the demands of a job, caring can be exhausting. You may need to pace activities and to ask for help from others so that you can have time for yourself. You might be able to make arrangements for a member of the family who lives further away to help you out on some days, or for a friend or family member to do specific tasks such as the shopping.

Community Care and Carers' Assessments

Community Care Assessment

After a diagnosis of dementia, you can ask Social Services to assess the needs of the person you care for, to see what kind of support will help them in their day-to-day life. This is called a Community Care Assessment. Depending on their needs, Social Services may arrange for them to attend a day centre, or for respite care, or someone to be with them while you have a break or catch up with things you need to do. Social Services may also recommend adjustments at home that will make it easier for the person to stay independent or for you to care for them.

Carers' Assessment

You are entitled to have your own needs assessed. This is called a Carers' Assessment. It will take into account the care that you give and any other demands on you, such as working or having a young family, or any health needs you may have (for example, if you have a long term condition that affects your ability to care). Depending on the assessment, Social Services may propose additional support for you. For example, you may not be strong enough to help someone who has mobility or balance problems when they are having a bath or shower. In this case, Social Services

may provide assistance with activities where it is difficult, and possibly unsafe, for you to help the person on your own.

You can arrange both Community Care Assessments and Carers' Assessments in several ways: you can ask your GP, or the Memory Clinic, or contact Adult Social Services directly. Assessments are usually carried out in the home of the person with dementia. They can be carried out by Social Services directly or by another professional they have appointed; for example, someone from your Community Mental Health Team for older people.

You can ask for repeat assessments if there is a change in your needs or those of the person you care for.

Some support from Social Services is provided without charge. The cost of other services depends on the income and savings of the person receiving the support. Each year your local authority will provide details of the charges it will make for its services and will make an assessment of any charges it will make to you and the person you care for.

You can find out more about Community Care Assessments and Carers' Assessments from your local Social Services.

Adult Social Care

- Reading: 0118 937 3747
www.reading.gov.uk/residents/care-and-support-for-adults
- West Berkshire: 01635 503 050
www.westberks.gov.uk/scip
- Wokingham: 0118 974 6772
www.wokingham.gov.uk/socialcare

If you become ill

Social Services support

If you are the only person caring for someone and you become ill or need hospital treatment, Social Services will provide emergency support to help the person you care for. Although you

may hope it won't happen, it makes sense to plan ahead in case of an emergency.

Registering with Crossroads Care

The voluntary organisation, Crossroads Care, helps with emergency care planning. You need to register in advance with them to set up a care plan which they will follow if you or emergency services contact them. They have 24-hour emergency phone lines. Once you have registered with them you can carry a Carers Emergency Card to show you have a plan. Crossroads cover immediate care. In the longer term, if needed, it is likely that Social Services will be able to support the person you care for.

Crossroads

- Newbury and District: 01635 30008
- Reading: 0118 945 4209
- Wokingham: 0118 979 5324

Crossroads 24 hour emergency service

- Newbury and District: 07867 673 063
- Reading and Wokingham: 0118 945 4218

Message in a Bottle scheme

If you are admitted to hospital as an emergency and, in the worst case, are unable to communicate about the person you care for, you can leave instructions for emergency services, using the Lions "Message in a Bottle" scheme. The scheme is free. You can get a special green plastic bottle to put in your fridge from GP surgeries and chemists or from organisations such as Age UK, council offices and police stations. The bottle comes with forms for you to fill out, to give details of the care both you and the person you care for might need. Emergency services know to look for the bottle when they arrive at someone's home.

Message in a Bottle

- For more Information:
www.southcentralambulance.nhs.uk/self-care/helpushelpyou/messageinabottle.ashx



Family dynamics

Family members may respond differently to the news that a relative has dementia and to the changes in family dynamics that can take place over time.

Sharing information and responsibility

If you can share care responsibilities with others in the family, or friends, it can help both you and the person you care for. Some families may have long-standing issues and disagreements that limit communication with one another. However, it is good to remind each other that any personal disagreements should not get in the way of caring. If you feel it's necessary, you could set down some ground rules that you all stick to; for example, agreeing to listen to, and consider, everybody's opinion when decisions have to be made. Try to remember to communicate regularly and share information that you receive; for example, from the Memory Clinic or from other professionals involved with the person you care for.

If you are not the main carer

If you are not the main carer, you can still provide help and support by

- making time to visit and spend time with both the person with dementia and their carer, or asking them to visit you for a change of scenery
- suggesting some things you can do regularly to help, such as a regular outing that will give the main carer a break
- making regular phone calls to listen, share ideas and be supportive
- helping with planning; for example, finding information about legal and financial aspects that are important in looking after someone who has been diagnosed with dementia.

Remember to be sensitive to the main carer's opinions and feelings. Ask regularly if there is anything more you can do to help.

People living alone without family support

If you are reading this as someone with dementia who does not have family support you may wonder how you will cope. Many people with dementia continue to live independently for a long time.

It's worthwhile making sure that people who know you and who you trust (for example, friends, neighbours, local shopkeepers) are aware of your situation. You may be able to get help to organise your home so it is easier for you to manage; for example, putting things you need everyday in cupboards that are easy to reach, and labelling them.

Your Memory Clinic will be able to advise you on assistive devices that can act as reminders and keep you safe at home. These are discussed in more detail on page 8 in the section on "Adaptations at home".

Be aware, though, that as dementia progresses, you will need extra support and that it is a good idea to plan for this early. Talk with friends and health professionals about how they can help you stay independent. You can ask Social Services and voluntary organisations about support services that can help you manage at home; for example, by doing shopping, laundry and helping with meals.

Make sure you have activities that will keep you in touch with other people. You can attend local activities; for example, Dementia Cafés, Singing for the Brain groups or gardening groups. See the "Support" booklet for contact details. You may be able to arrange transport to these activities via your local Social Services or voluntary groups.

Making a new home

Decisions about where to live

For some people, the changes that come with dementia may prompt a move to a new home. They may:

- choose to move to sheltered accommodation or to a care home because they feel they are safer there or that their life will be simpler

- agree to move somewhere that is nearer to family or to move in with family
- need to move, even though it is not their choice, because their care is too complex to manage at home. For example, they may need 24 hour care because they may wander at any time of day or night
- have other illnesses, as well as dementia, that make it difficult to care for them at home.

Feelings about moving

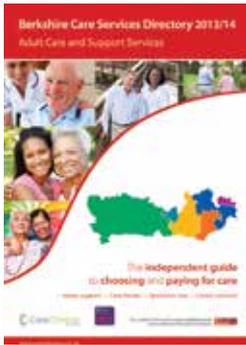
Even when a person chooses to leave their home, the change can be difficult for them to get used to. If they have not made the change out of choice, the idea of moving and the change itself can be the cause of both anger and sadness. A move may increase their confusion and they may frequently ask to go home.

Moving a relative or friend from their own home can also be difficult for you as their carer. It may feel as though you are giving up on them, but in some cases, looking after someone with dementia can put the carer's health at risk. Sometimes residential care may be the only option.

The person you care for has the right to be consulted about a planned move. If they are able to make choices you should take them to see the home or homes you are considering and listen to their opinion about them. If they cannot make choices for themselves and you are acting on their behalf, you should make the choice in their best interest. If they have strong feelings against the home you are considering you should try to find alternatives.

When someone moves they should be able to take as many familiar things with them as they wish. Even if they are moving into a care home they may be able to take a favourite chair, pictures, books and other mementos that are important to them; and, of course, familiar clothes, shoes and personal care items. If someone has a pet which cannot go with them to their new home, voluntary organisations, such as the RSPCA, may help to find a home for it.

Guides to choosing a care home



Berkshire Care Service Directory is published each year and gives guidelines on choosing care homes, as well as a listing of the different kinds of homes in Berkshire. It is available online from www.carechoices.co.uk and printed copies are available from Memory Clinics and from support organisations.



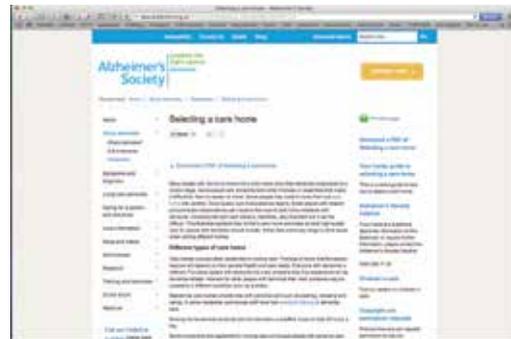
Wokingham Borough Council has its own advice service, Optalis. See www.optalis.org



The NHS provides guidance on choosing a care home:
www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Carehomes.aspx



Age UK provides a guide and checklist for people choosing a home. You can access this online at www.ageuk.org.uk/home-and-care/care-homes or by contacting Age UK by phone on 0800 169 6565 or by visiting one of their local offices.



Alzheimer's Society has a fact sheet, number 476, about choosing a care home: www.alzheimers.org.uk/factsheet/476



Social Care Institute for Excellence is a charity which provides a care-finding service for England and information via its website, Find Me Good Care: www.findmegoodcare.co.uk



Adaptations at home

Caring for someone at home can be made easier by a range of changes. Some quite small adjustments, such as improving lighting, can make a big difference.

A Community Care Assessment, carried out by your local Social Services, will advise on adaptations or equipment that could make home life easier and help the person you care for stay independent.

Contact details for Community Care Assessments are on page 4 in this booklet.

Memory aids

Many people with dementia have difficulty remembering everyday things that they have previously taken for granted; for example, remembering the day of the week, remembering to take their medication, or to

turn off their cooker or taps when they have finished using them. Some lapses in memory may not be so important but others can result in inconvenience or risk to a person's safety.

If you are living with the person you care for, you will be able to help with prompts and reminders, but you may not be there all the time, so memory aids can still be useful. Someone living on their own may need several different memory aids to help them cope.

The following paragraphs give some suggestions for aids that may be helpful.

Simple memory joggers



Very basic aids, such as notes and reminders, clearly written and put in the place where someone carries out an activity can help; for example, reminders to check taps are turned off or to take keys when leaving the house. It can also help to provide reminders of what things go in cupboards or drawers, for example in a kitchen or bedroom. Clearly written labels or picture labels attached to cupboard doors or drawers may be useful.

If someone finds it hard to remember which room is which in their house it can help to keep doors open. This can be particularly important for the toilet, as not remembering where the toilet is can prevent people from getting there in time.



Clocks that show the time of day, including whether it is day or night time, and the day of the week, can also help someone who cannot remember these easily.

Programmed devices



More complex memory aids can help someone stay independent for longer. For example, small alarm devices can be programmed with voice prompts, to tell someone it's time to take their medicine, or have lunch, or go to bed. These

need to be in a place where the person will hear them. Some alarm devices can be worn on a belt or the wrist. Others can be put near the place where the person needs a reminder; for example, by the front door. They will be triggered either by opening the door or by the person passing through a beam that triggers the reminder.



It's a good idea to start using these devices while the person is well enough to find them easy to respond to. It's hard to judge when is best but it is worth trying them before you think they are really needed. Some need practice to learn how to use them properly. You can only find out if they will help by trying them. Some aids may just be too complex to learn.

Medicine containers



There are special containers to help people take medicines at the right time. Simple pill trays with compartments for each day and time of day, can help keep someone on track. More sophisticated versions have compartments that you can program to open automatically at the time the pills should be taken. These sometimes have a sound alarm or flashing light as an additional reminder. Or a person's pharmacy can make up their pills in blister packs, with compartments for doses on different days of the week.

While pill dispensers and packs are useful it's wise not to rely on them but to check that the person you care for is taking their medication at the right time. They may take pills out of the box but still not remember to take them. If the pharmacy is filling blister packs you should check that these have been filled accurately

with up-to-date prescriptions. As with other memory aids, it can be useful to get someone used to using these packs before they are completely reliant on them.

Phones and remote controls



You may find it helpful to replace everyday home technology, such as phones and TV remote controls, with large button versions that are easier to see and use than standard versions. Phones can be programmed and their buttons clearly labelled with names or pictures of the important people someone might want to call.

Physical safety

Detectors and sensors



Reminders may not provide enough support on their own. You may need to add safety sensors that alert the person or you if there is a problem; for example, gas or smoke detectors in kitchens and flood detectors in bathrooms. Detectors can sound an alarm in the house.

Sensors can also be used to turn on lights when the house gets too dark, reducing the risk of falls, and to turn them off again when it is light. Similarly thermostats can be used to control heating and ensure a house does not get too cold or warm.

More sophisticated sensors, such as pressure mats and motion detectors can detect whether a person has moved from their chair or bed and can sound an alarm to alert you. There are also sensors that can detect if someone hasn't moved, which may mean they have had a fall or left their house and not returned. The person you care for may also agree to wear a pendant alarm that they can press to alert you if they fall, or are lost, or run into other problems.



Different kinds of sensors can be combined and linked to a telecare system, which can contact you or a care service if activated by someone's movements.

Removing physical hazards

People's safety can also be improved by simple checks around their home to remove hazards. Look out for:

- loose mats or furniture in the way of their typical routes across rooms
- dark places where lighting could be improved
- highly patterned floor surfaces which can make it difficult to judge depth, for example, on stairs
- mirrors that might give a misleading impression of a space ahead to walk into
- stairs where a stair gate or door could prevent the risk of falling.

There are many aids that can increase safety. You might consider:

- grab rails; for example, on stairs, by the toilet, in the bathroom or shower
- support frames around toilets
- perch stools for use when washing at a basin, or bath or shower seats
- bed rails that can prevent a person from falling out of bed

- raised chairs and toilet seats to make it safer and easier to sit down and get up.

The changes you make will depend on the needs of the person you care for. You need to balance creating a safe place for them to move around with the risk of changing too much, too rapidly. As far as possible you should talk with them and get them involved with the changes you plan to make.

Mobility aids

Many people with dementia become less mobile than they have been previously. Sometimes this is just a normal part of the ageing process but often it is a result of changes in the brain's ability to control movement. A walking stick or frame may help at first but as time progresses some people may need a wheelchair. Depending on where they live they may need a stair lift and possibly a hoist to help them get in and out of bed.

It is important for you not to struggle too much to help the person move. An injury to you from a fall with them may mean you cannot care for them. You should contact Social Services to ask for an assessment of the aids that they may need. Unfortunately, while walking sticks, frames and wheelchairs are likely to be provided free, you may need to hire, lease or buy more expensive aids.

In order to help someone stay at home you may consider options such as moving their bedroom downstairs or putting in a shower room so that they do not have to use a bath. Major adaptations to someone's home cannot be funded by Social Services but work, such as installing a shower room, is exempt from VAT. See the section "Daily living equipment and adaptations to your home" on page 5 in the "Legal and money matters" booklet.

In some cases, a person's home may become too difficult for them to manage and it will be time to consider whether they should move; for example, to sheltered accommodation or to a care home. The process of making this decision should be made with the person

themselves, as is discussed in the section Making a new home on page 6 in this booklet.



More information

The Foundation for Assistive Technologies has a useful brief guide to memory aids on their website

- www.fastuk.org/fastdocuments/Getting_Equipped_to_Tackle_Forgetfulness_small_version.pdf.
- Or you can ask them to send you the guide by calling 0300 330 1430.

There is more detailed information on memory, safety and mobility aids in factsheets from the Disabled Living Foundation which can be found on their website

- www.dlf.org.uk/content/full-list-factsheets

For information about choosing assistive technologies and advice on selecting products visit

- AlzProducts
www.alzproducts.co.uk
- AT Dementia
www.atdementia.org.uk

* Product images in this section kindly supplied by AlzProducts. © AlzProducts 2014



Adaptations for behaviour

Responding to a person's changing behaviour can mean some new routines but can also open up new activities and contacts that can be enjoyable both for the person you care for and for you.

The different types of dementia can affect people's memory, thinking, reasoning, language and co-ordination. This means the person you care for may need help to do many of the things they used to manage without any problem.

Dementia can also lead to changes in a person's behaviour; for example, they may say or do things that they would not have done before. They may become restless, start hiding things, lose interest in things, perhaps become too trusting or become accusatory or uncharacteristically rude.

Your detailed knowledge of the person you care for and their lifestyle, likes and dislikes may help you to understand what they might be feeling and why their behaviour has changed. You might be able to respond by adapting your plans to make things easier for them. But you might not always get it right first time. You may have to go through a process of trial and error to find out what best meets their changing needs.



Communication is an essential part of responding to a person's needs. There is advice on communication at www.bupa.co.uk/Dementia-Care

Unexpected reactions

Changes in behaviour are often linked to the emotions someone feels because of the losses they experience with dementia. The person you care for may be unable to explain why they have done something or reacted in a certain way, and could feel threatened if asked directly "Why?". Try to be patient and look out for patterns that lead to uncharacteristic behaviour; for example, busy or noisy environments.

Define the problem

- Exactly what happened?
- When?
- For how long?
- Is there a pattern?

Consider the cause and how the person is feeling physically and emotionally

- Have they misunderstood what was said or done?

- Are they frustrated because they cannot manage something on their own?

Consider how you reacted

- How did your reaction affect the person?

Think of new ways to respond to similar situations in the future. It may help to discuss the problem with someone else, such as your GP, a professional from your Memory Clinic team or another person who has experience of caring for someone with dementia. Discuss your feelings, too, as dealing with sudden changes in behaviour can be demanding emotionally.

Persevering with this approach to new behaviour can reduce some of the stress involved and improve the quality of the relationship you have with the person. If the changes you make do not help go back to the professionals you have spoken to for more advice.

Case study: adapting to keep someone safe

My mother often leaves her flat without telling anyone where she's going. She's walked back to her old house a couple of times, crossing several main roads. She goes out at any time of night or day, in all weathers. She won't get in the car to come back with me and I'm worried that, to anyone passing by, it must look as though I'm bullying a frail old lady.

The carer talked with her support worker from Berkshire Carers, who suggested several strategies:

- fixing alarms on the doors of the house so that she knew when her mother was going out
- making sure that her mother carried ID with a name and telephone number of a contact; ideally on a clearly visible pendant, if she would agree to wear one, so that people would be able to help her get home

- driving her mother past her old house frequently, when going out for other reasons, so that her curiosity and anxiety about it was reduced
- if she needed to collect her mother, using an offer of something better to do, depending on time of day (go to visit someone else, go home to watch a favourite DVD, go out for a coffee).



Case study: adapting to keep someone healthy

My wife got angry after breakfast when I found her looking for biscuits in the cupboard and asked if she was still hungry. She tried to hide what she was doing. She told me to stop interfering. I am worried about her eating as she is



putting on weight but she obviously feels she needs the food, or maybe doesn't have the self control she used to have. I think she was angry because she used to be "in charge" in the kitchen and make all the decisions about meals. So it must have felt wrong that I was questioning her.

The carer talked with a Memory Clinic nurse about whether he should be so concerned that his wife was eating more. He mentioned that he liked to keep biscuits in the house for people who visited. With the nurse he agreed to take a more relaxed approach and leave just a few biscuits in the tin for his wife to snack on but also to leave out healthy snacks such as sliced fruit. He also kept a separate store of biscuits for visitors.

Case study: adapting to avoid conflict

I find it very hard to get my father to take his pills, particularly at night. He has difficulty swallowing and sometimes chokes on them. He always questions whether I am giving him the right pills and sometimes refuses to take them, often being very insulting to me. It's upsetting but also makes me worried because he needs the pills for his heart.

The carer talked with her father's GP about whether there were other types of pill that would be easier for him to swallow, and whether she could reduce the number of pills he needed to take at night. The GP suggested changing the timings for the pills

so that the most important ones were taken in the morning. One of the pills was swapped for a liquid medicine that was easier to take. Her father remained suspicious about his medicines but the friction was reduced by these changes.



Lack of interest or response

Some people with dementia can appear withdrawn or uninterested in people and things around them. This could be a result of their reduced ability to recognise people or places, or to plan and initiate tasks or conversation

independently. It could also be that their hearing needs to be checked. You can help by initiating activities and conversations. Try not to be too demanding but to talk about things that are familiar and positive. For example, talk about family members the person likes, reminisce about things they have done in the past, go

to familiar places for outings. A different place from home may engage them or prompt their memory. Even if they cannot talk about it they may enjoy walking around and seeing different things. Friends and family can also help by visiting you and talking about their news or by inviting you to visit them.

Local activities, such as Dementia Cafés and lunch clubs, or activity groups can be enjoyable and stimulating. If you are able to go to these activities, they can give you an opportunity to talk with others in a similar situation and sometimes get helpful tips from their experience.

See more about activities for people with dementia in the section “Getting out and about” on page 20 in this booklet, and also see contact details for activity groups on page 12 in the “Support” booklet.

The person you care for may have a general lack of interest in things because they are suffering from low mood. This might be because of their diagnosis of dementia, because of changes that are happening to them or for some other, unrelated reason. If you think that the person is feeling low, you should try talking with them about their feelings to see if it helps.

Gentle activity, such as visiting a local park or garden centre, if they are able to walk or go in a wheelchair, may help lift their mood. If you see a steady dip in their mood and they become increasingly withdrawn you should ask for advice from your GP or Memory Clinic nurse. There may be medication or other therapies that could help them.

Anxiety and agitated behaviour

People with dementia may experience feelings of anxiety as part of their dementia or as a reaction to the changes that are happening to them. If you see they are anxious you should try talking to them about what is upsetting them and giving them reassurance. If something is making them anxious (for example, an outing they don't want to do) you may want to postpone it until they are able to cope with it.

If you need to take the person out, for example, to go to the doctors or dentist, and you know they will be anxious, it may help to have another person with you. Most health professionals (including dentists and chiropodists) will visit a person in their home if they know it is very difficult to get them out. Other people, such as hairdressers or beauticians, may come to a customer's house if you ask them. These kinds of visits can help someone stay in touch with the life they used to have and things that have been important in the past.

Anxiety may make someone with dementia very dependent on the person they see as their main carer. They may be particularly anxious if you are not around, which can be difficult for you if you are working or need to go out for other reasons. If you are going to ask other people to be with the person you care for while you are out it is worthwhile getting the person used to the idea early on, so that it becomes a routine. This will be better for them, and allow you to relax more when you are away from them.

There are many techniques you can use to reassure someone who is anxious. Some may be more effective than others:

- acknowledge that they are anxious about something and talk to them about it rather than dismissing it or trying to explain it away
- make eye contact as you talk to them
- sometimes touch (for example, holding their hand or stroking their back or arm) can help
- take time to reassure them, and try to avoid correcting or contradicting them as you do so
- if you need to explain something, such as, why you are going out, use simple short phrases in a low calm voice.

If someone is highly anxious and agitated these kinds of techniques may not be enough on their own and you will need to talk with your GP or Memory Clinic nurse about what can be done to help them. There may be medication that can help.



Tips for reducing stress

The following listing is a reminder of some day-to-day techniques that can make things more comfortable and reduce stress for you or the person you care for.

Consider physical as well as mental health

Physical problems can sometimes lead to changes in a person's behaviour. If the person you care for suddenly seems more confused or agitated than usual or has a series of falls, it could be due to their medication, or an infection. Urinary tract and chest infections are particularly common in older people. If you're concerned either about a possible effect of medication or an infection, contact the GP. Other physical problems, such as pain, failing eyesight or hearing, can also lead to changes in behaviour and may make someone seem confused or withdrawn.

Allow plenty of time

Try to avoid crowding too many things into one day. It often takes longer for someone with dementia to do routine things, such as getting dressed. It may help to avoid activities first thing in the morning, or following directly on from another. It may be better to plan only one activity in a day, and have some quiet days at home. Some people have more energy than others but

even a visit from friends or a trip to the doctor can be tiring for someone with dementia.

Have a routine

A routine that is reasonably consistent, for example specific days of the week for activities or visits, can help orient someone with dementia. If they are living alone, a routine can help them to plan and be ready. Writing things clearly in a calendar and reminding them of upcoming activities can also help.

Use the best time of the day

Most people have times of day when they are more alert than others. Try to plan around these times. For example, it may suit the person you care for to be active in the mornings and have a rest in the afternoon; they may enjoy their main meal more at lunchtime than in the evening. Some people with dementia can be particularly confused or agitated in late afternoon or early evening. Everyone is different and the routine that suits one person may not work for another.

Avoid conflict

A person with dementia may believe things that are not true. These may be simple things, such as mistaking the day of the week; or more difficult, such as thinking they can visit someone who is no longer alive, or that something important, such as paying a bill, hasn't been done. They may get distressed if you try to correct them. Try to divert their attention. If you can find an underlying reason for their anxiety, reassure them. Sometimes you may have to help them see they are wrong; for example, if they want to go out in the early hours of the morning. If conflicts are frequent ask for advice from your GP or Memory Clinic.

Keep things calm

Some symptoms of dementia can eat away at your patience, particularly repetitive behaviours, dependency on you or erratic sleep patterns. Getting cross will upset the person you care for and make you feel guilty. If you do get cross, don't forget to say sorry and comfort them. Some things may help to calm them, such as a cup of tea, or looking at a family photo album, but these don't always work. Being able to take time away can help you keep patient. You may be able to ask a relative or friend to be there in your place; or arrange for the person to attend a day centre or for a support worker to take over for a while. If you feel you're being short tempered ask for help from your GP or Memory Clinic.

Remember that new information can be difficult

A person with dementia will find it easier to remember familiar information than anything new, whether it is a new person, place or routine. For example, if they are prescribed a new medicine, they may not remember that they should take it, or why. They may become suspicious about it and query whether they should have it. Whenever you do something new, you may have to repeat reminders and explanations. Keeping things as familiar as possible will reduce the stress of new demands.

Keep choices simple

Decision-making can be hard for someone with dementia, so try to give them very simple choices rather than a range of options. For example, rather than expecting them to find their clothes and get dressed you may get their clothes out for them, or give them a choice of "red jumper or blue today?". Similarly with choices of food: rather than asking "what would you like to eat this evening?" you may need to make decisions, with some options, such as "jacket potato or soup tonight?".

Help to start activities

A person with dementia may be confused by everyday tasks, such as eating, brushing teeth or getting dressed. If you can help with the first stages (for example, putting the knife and fork in their hands, or cutting up food so they can put it on their fork) you may find they are then able to take over and carry on the activity themselves.

Keep involved with your friends



Some friends cope better than others when someone they know has dementia. Most friends will want to keep on including you in their lives but may not know the best way to do it. Visits to or from friends, particularly people who you have known for a long time, can provide links to memories and new topics of conversation. You may need to be sensitive, too, in case the person you care for enjoys seeing some people more than others, or prefers to see just one or two people, rather than a group.



Everyday activities

It's helpful for someone with dementia to have activities to do at home. Involving the person you care for in everyday things can help keep their mood positive, provide opportunities for conversation and keep their mental and physical skills going.

Activities are just as important if someone is living in a care home, as in their own home, although you may need to choose activities that fit with the home's routine.

Build on familiarity

Activities that work best are likely to be ones that the person already has some interest in. For example, if they have been a keen gardener or interested in cooking, they may be happy to help in those activities.

Be flexible

Keep the tasks you suggest simple. So, for example, a person who may not be able to follow a cake recipe might help with cake making by stirring the mixture; or a person with an interest in gardening might help with sweeping leaves or planting seeds, depending on their physical health.

If the person has a hobby, such as painting, collecting stamps or knitting you may be able to help them set up their equipment so they

can continue with it. They may not be able to do things as well as in the past. Be careful not to criticise or correct and watch that they do not become frustrated. If something appears to be too difficult, try adapting the activity; for example, helping you look through and sort old paintings in their collection, or looking at and talking about old knitting patterns they may have kept.

Some people may need short instructions and reassurance (for example: "hold the spoon here...", then "put it in the bowl...", then "you can stir the mixture") and gentle prompts for getting started.

Focus on enjoyment

An activity with an end result can give a sense of satisfaction; for example, a pile of leaves that can be bagged up or made into a bonfire, or a cake that can be shared. But if you get the feeling the person isn't enjoying the activity, don't force them to complete it, even if it's something they have enjoyed in the past. It may be that their likes and dislikes have changed. End results are satisfying but enjoying the task should be the priority.

Join in the task

A person is much more likely to want to take part in an activity if you join in with it enthusiastically. Your energy will encourage them.

There are also many shared activities a person can enjoy, without being particularly energetic. For example, you may be able to do crosswords or puzzles together, or play games such as draughts or dominoes. They may enjoy you reading books or newspapers to them, or looking at things that will jog their memory, such as old football match programmes. You can also share listening to music or watching films that they are fond of. If there are films, TV programmes or videos that match their interests (for example, in wild life, travel or sport) these may be particularly enjoyable and help spark conversation.

Memory albums



Another way to keep up conversation and activity is by making an album of memories of a person's life; for example, using photographs, postcards and newspaper cuttings that show them and events from their early years, through to the present day. You can keep on adding to this; for example, if you have a special event in the family, or a visit or holiday that the person has enjoyed. Working to create the album together can be an enjoyable activity for both of you. Label the things you put in the album with easy-to-read text so that the person can look back through it if they want to. You can get more advice about how to make a memory album of this kind from voluntary organisations.

Memories can also be stimulated by a familiar object, such as an ornament or toy, or something with a scent; for example, a lavender bag. You might try these other routes to stimulate memory, as well as a memory album.

Activities with other people

Many people with dementia and their carers enjoy getting involved with local activities, such as Dementia Cafés and lunch clubs, or activity groups such as Singing for the Brain or gardening groups. These kinds of activity give an opportunity to talk with others in a similar situation. See more about these kinds of activities on page 20 of this booklet.



Getting out and about

You may enjoy going out and travelling with the person you care for. A little planning ahead can smooth arrangements and make the experience comfortable.

Embarrassment

Until recently, the topic of dementia was not discussed much in public. One of the sad consequences of this has been that some families have been embarrassed to take a relative or friend with dementia to public places. They may worry in case the person's behaviour attracts attention or leads to negative comments. Attitudes are changing and if you can provide support for the person you care for and include them in the activities you are involved in (within the bounds of safety) it will mean they are able to enjoy more variety.

Local activities

A diagnosis of dementia does not mean someone has to completely change their activities and it is far better to continue with normal day-to-day life as long as it is manageable. So if, for example, a person attends a social club, exercise class or interest group, try to keep going with those as long as they are comfortable with them.

In any group of people, particularly older people, there are likely to be one or two who have difficulty with mobility or with their memory. Often social groups organise

themselves informally to help one another. If the person you care for is beginning to have some difficulties it might be worthwhile telling other people in the group, or the group organiser, so that they help if necessary. It's

just something to keep an eye on, rather than making sudden changes.

You might want to start some new activities that are organised for people with dementia and their carers. They can be a good way to meet other carers.

Activities organised for people with dementia

Local activities in Berkshire are shown below. Contact details for activity groups can be found in the "Support" booklet.

Activity venues and times sometimes change. Before going to an activity, check that the information given here is up-to-date.

Dementia Cafés

Sometimes also called Alzheimer's Cafés or Memory Cafés. These are held on regular days at different places throughout Berkshire. There is normally some activity to enjoy (such as a quiz) and an opportunity to chat with other people. They are organised either by the Alzheimer's Society or Age UK (Age Concern).

Exercise classes

Physical activity can keep someone mentally stimulated and reduce the risk of low mood. Age UK run a programme called "Active Living" which includes exercise classes and physical activities, such as walking. Some of their exercise classes are seated so can be suitable for people with limited mobility. The Alzheimer's Society also runs exercise classes. There are also local gardening projects that can be an enjoyable way of keeping active.

Musical activities

Music can improve people's mood and calm their behaviour. Even if they don't sing they may enjoy tapping out rhythms or dancing. They may remember music from the past when other memories are lost. If the person you care

for has belonged to a music group or choir they may want to continue with that as long as they feel able. The Alzheimer's Society runs "Singing for the Brain" groups across Berkshire for people with dementia and their carers.

Reminiscence activities

Some groups, such as Dementia Cafés and day centres or libraries, run activities based around memories of things from the past. You may also have things or photographs at home that you can use to start a reminiscence conversation. Or there may be a place that you could visit that might prompt happy memories.

There are collections of reminiscence objects at the Newbury Library and Reading Museum, which you can visit or borrow. But it may be that the person you care for is more interested in things that they remember from their own past. With this in mind, remember that not everyone enjoys reminiscing about their past.

Day centres

The person you care for may attend a day centre at times when you are not able to look after them. Most day centres have activities similar to those described in this section. There is a list of day centres in the "Support" booklet, page 8.

As with all new things, it will probably be easier to join a new group at an earlier stage after diagnosis than later and this can be useful in helping someone stay active and involved with people as time goes on.

Day trips and holidays

Many people enjoy the freedom to travel either for day trips or for longer holidays. When someone has been diagnosed with dementia they may decide to do as much travel as they can while they are still able. Or they may be less confident about travelling and prefer to stay close to home. There are no hard and fast rules about travelling. Much depends on the preferences of the person and how well they are at the time of diagnosis.

Holidays are for relaxation. They should be a time for you and the person you care for to enjoy a break from home, so trips that are likely to be stressful may be best avoided. Travelling to familiar places, with shorter journey times, may be easier than discovering new, distant places. Think through the details of any trip you plan. Many hotels and some B&Bs have accessible bedrooms that may be helpful for people with mobility problems.

You also need to consider whether the place you are going is accessible outside the hotel room. You can ask transport providers to provide help at airports and stations. You may need to have plans for what to do if there are delays and the person you care for becomes tired or distressed. If they are taking medication, make sure you have it with you, in case of delays.

Taking other people with you will add to the enjoyment of a holiday. It may provide company and may mean that you have more of a break if you can share looking after someone with others.

Check any holiday insurance you take out, so that you know the person with dementia is fully covered. Some insurers will not cover a person if they have a problem that is a direct result of their dementia but there are insurers who specialise in covering people with disabilities.



The Alzheimer's Society Factsheet 158 provides a good checklist of things to consider when thinking about holidays www.alzheimers.org/factsheet/158

Driving and transport

Driving demands levels of attention and speed of reaction. These may be reduced in someone with dementia or mild cognitive impairment. If a person has been diagnosed with dementia they must inform the DVLA. Failing to do so could result in a fine (see page 1 of the booklet "Legal and money matters" for more details). A person with a diagnosis of dementia should also inform their car insurance company.

The DVLA will then make a decision about whether the person is able to continue driving. After this decision, they will either withdraw their licence or continue their licence for a period of one, two or three years. You may have to suggest that they give up driving in order to keep them and other people safe.

As a carer you have a responsibility to inform the DVLA of any change in a person's ability to drive. If you need advice about this, contact your Memory Clinic or a dementia advisor.

Even if someone has been told they are still safe to drive you might want to consider the following tips to improve their safety:

- keep to short journeys, along routes they know well
- avoid busy areas or times of day
- avoid night or bad weather driving
- leave plenty of time for the journey and do not let them drive if they are stressed or upset.

If you are unsure whether a person should still be driving you can book a driving assessment, for a fee, at your Regional Driving Assessment Centre. After the assessment a person is given immediate advice followed by a confidential report.

Remember that there are alternatives to driving. If your annual mileage is low, giving up your car and using taxis and buses will be cheaper. You may be entitled to use Council transport for people with disabilities.

The councils in the west of Berkshire provide information about transport services but not in one place. Current guides can be downloaded from the web:

- Reading has a journey-planning website www.reading-travelinfo.co.uk/journey-planning.aspx
- West Berkshire (Newbury) currently has a leaflet "Getting there" which can be downloaded from their website www.westberks.gov.uk/CHttpHandler.ashx?id=19478&p=0
- Wokingham has information on its website www.wokingham.gov.uk/transport/travel/disabled/



For more information about driving assessments see www.rdac.co.uk/services_driving.php

Berkshire Healthcare has a detailed information leaflet "Driving and Cognitive Impairment" which is available from your Memory Clinic.

The DVLA can be contacted on

- Telephone: 0300 790 6806
- Website: www.gov.uk/contact-the-dvla

Blue Badge parking

If either you or the person you care for is unable to walk or finds walking difficult you may be eligible for the Disabled Parking Scheme (the Blue Badge scheme). If you have a Blue Badge you will be able to park closer to places you are visiting. If you do not have your own car but use taxis, they can also use your Blue Badge to park closer to your destination.

You can apply for a Blue Badge by contacting your local council offices

- Reading: 0118 937 2033
- West Berkshire (Newbury): 01635 503 276
- Wokingham: 0118 974 6800



Caring for physical health

Physical health problems can be difficult to recognise in a person with dementia and, as dementia progresses, the person you care for may not be able to tell you about symptoms they are experiencing.

People with dementia tend to be diagnosed with infections and other illnesses much later than people without dementia. This is because the person may not recognise their symptoms or talk about them. Symptoms may also be difficult for carers and medical staff to see. The result is often that problems are spotted later, when they are hard to treat and may need hospital treatment.

It is important to be aware of the common physical problems that can affect people with dementia. If you act on early symptoms you can help avoid unnecessary suffering and may prevent stays in hospital.

Infections

The person you care for may develop an infection and not realise they are unwell. The signs and symptoms of dementia vary. If you notice that someone's symptoms have suddenly become worse, for example, they are more confused or aggressive, you should ask your GP to check for an infection.

People are more likely to fall if they have an infection. They may also become suddenly confused over hours or days and have hallucinations, seeing people and things that are not there. At first this may seem like another symptom of their dementia. But if you know someone's normal behaviour, you will probably know when that pattern changes. If

you see changes, ask your GP for a check to rule out infection. Similarly if the person is in hospital, you may see changes that the hospital staff have not noticed. Tell staff about them.

Pain

A person with dementia may not talk about being in pain, but could be in severe distress. This may show as agitated or irritable behaviour. Doctors often prescribe painkillers like paracetamol to use “as required”, but then they are not given because the person does not ask for them. Learning to recognise signs that someone is in pain and giving them regular pain medication could help.

Pain checklist

This checklist sets out some signs that might show someone is in pain which they cannot describe. If you notice any of these signs, mention them to their GP or medical staff caring for them:

- crying out, particularly when they move or are helped to move
- tense expression on their face
- change in body language, particularly protecting a part of their body
- changes in behaviour: either becoming quiet and withdrawn or increased movement, shouting or swearing.

See the “Pain assessment” scale in the “Record keeping” section for more information on recognising and monitoring pain.

Some conditions such as arthritis, fractures, pain following an operation, or cancer may require strong painkillers. A specialist pain nurse or doctor may give advice on use of these medicines. They often cause side effects, such as drowsiness and constipation, so the dose needs to be adjusted carefully.

Skin condition

A person’s skin can change as they get older. It may become dry and flaky. This could make them itch, leading them to scratch and bruise their skin. Regular moisturising will help. Try to check their skin regularly at bath or dressing time.

If a person has bladder problems and is not kept clean and dry, their skin may become irritated. Any red or damaged areas can quickly turn into pressure sores. If you notice any skin changes, tell the GP, district nurse, or care staff looking after the person, so they can take immediate steps to prevent pressure sores.

Falls and mobility

Falls are very common. They are amongst the most common reasons why people with dementia end up in hospital. Falls can lead to fractured wrists, hips and ribs, or to cuts and bruises. After a person has had a fall they may develop a strong fear of falling, and anxiety.

In many cases, falls can be avoided. They are more common when a person cannot see well, has balance problems or trips over hazards such as footstools, rugs and loose carpets. Other medical reasons for falls can be heart conditions, changes in blood pressure, having an infection and unsuitable medication.

If a person has had two or more falls in the last year, they are described as being “high risk”. There is a special service to help people who are at risk of falls and you should ask your GP for an appointment to see them.

Incontinence

As dementia progresses, people may have problems controlling their bladder and bowel (called “incontinence”). There are many causes of incontinence that are not a result of dementia: infections, the medication a person is taking or constipation. Incontinence can also be caused by prostate problems in men or prolapse of the womb in women.

With dementia, some people have problems recognising the feeling of needing to use the toilet, or cannot say they need to go or cannot get there quickly enough. They may no longer recognise the toilet.

Continence problems can make a person anxious and not want to leave the house. Their sleep may be disturbed and, if they get up because they are wet or soiled, they are at risk of falls. So it is important to talk with their GP or a specialist incontinence nurse to get advice.

When incontinence is caused by a bladder infection it must be treated by antibiotics. Infection is diagnosed by tests of urine samples, but these tests can sometimes be inaccurate. This may mean that someone is prescribed antibiotics unnecessarily. So if a person has had two courses of antibiotics in a short space of time, they may need further investigation to find out if there is another cause of incontinence that has been missed. A review by an incontinence nurse could also help. You can ask your GP to make a referral for a review.

Constipation

Many older people suffer from constipation, particularly if they are less active than they used to be. Scar tissue from operations people may have had in the past can also make the bowel less efficient. Some conditions, like Parkinson’s disease, can affect the bowel. Constipation can also be a side effect of some medication.

In people with dementia, loss of appetite may mean they are not eating enough fibre or drinking enough fluids to keep their bowel working regularly. They may not go to the

toilet when they need to and this can cause constipation. You need to help the person you care for to follow a diet that will help reduce constipation. If it is possible encourage gentle exercise, for example, walking around the garden.

Severe constipation can cause bloating and pain and, sometimes, leakage from the bowel, which might be mistaken for incontinence. If the person you care for suffers from these symptoms, contact your GP or district nurse for advice on how to help them.

Frailty

The person you care for may not be eating or have as much energy as before, and could be becoming more frail. Frailty can increase the risk of the physical problems described above. The following frailty checklist shows changes you need to look out for and discuss with your GP:

Frailty checklist

- weight loss of more than 10 pounds in the last year
- weakness and decreasing muscle strength
- exhaustion or low endurance and energy levels
- slowness
- low physical activity levels



Hospital visits and stays

It is very likely that the person you care for will need to visit hospital, either as an outpatient or to stay. Hospital routines can be difficult for someone with dementia but you can help them by liaising with hospital staff.

Hospital appointments

Taking the person you care for to hospital outpatients appointments can be stressful. Planning ahead can help. If an appointment is scheduled too early for you to get there comfortably, phone the clinic and ask for a later time. It may help to explain why.

All local hospitals have reserved spaces for people with a Disabled Parking Scheme badge (Blue Badge). If someone needs help getting from the hospital car park or public bus stop to the clinic, phone the hospital ahead of your appointment and let them know when you will be arriving. They should be able to send someone to help you.

Numbers for assistance with transport are

- Prospect Park Hospital: 0118 960 5000
- Royal Berkshire Hospital: 0118 322 7049

- West Berkshire Community Hospital: 0118 322 7049
- Wokingham Community Hospital/ Barkham Day Hospital: 0118 949 5000

Note that some hospitals may ask you to arrange transport via the GP.

Staying in hospital

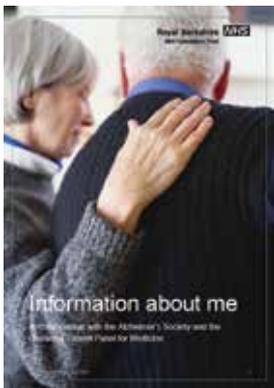
If the person you care for is admitted to hospital, staff may not be aware of their dementia. Please let them know.

Tell staff what things will make the person you care for comfortable and if there are other things that might upset them. You can ask to talk to the nurse responsible for them, or to the ward sister, to explain their usual routine. These details can be put in the person's notes.

It can be helpful if you write out the key things that are important; for example:

- whether a person likes to be called by their first name or not
- the kinds of foods they like and how they take their tea or coffee
- any allergies or reactions to specific medicines that they have
- whether they need help with personal care, for example, brushing their teeth or taking out and putting in false teeth, and so on.

On some wards a booklet called “Information about me” is provided for you to record details that are important. But even if you are not asked to fill in one of these booklets, nursing staff will still need the information you can provide to look after the person well.



There may be things someone with dementia will find difficult to do for themselves, such as choosing their meals from a hospital menu, asking for drinks and drinking itself, or getting to the toilet. Local hospitals have a Carer Passport scheme which allows you to be on the ward with the person you care for at any time. This will reassure them. It also means that you can help with their care (for example, washing, dressing and feeding them) if needed.

If you cannot be on the ward with someone and you think their care needs are not being met, ask to talk with the ward sister to explain their needs and routine.

Berkshire hospitals use a “red tray scheme” to signal to staff that a person needs help with eating and drinking. If you have concerns, you could ask for a person to be included in the scheme. Many wards also have volunteers to help patients at mealtimes.

If you have questions about hospital care

Your first point of contact on the ward is the nursing staff. You can speak to them in person or phone the ward to talk to them.

Every hospital patient has a doctor who is responsible for their medical treatment and also for decisions about when they are well enough to leave. If you would like to talk to the doctor but cannot see them on the ward you can ask for their phone number to arrange a time to talk.

Local hospitals have liaison psychiatry teams who work across all wards. Their specialists in dementia care can be consulted about problems.

If you notice changes in the person’s condition (for example, if they are more confused than usual) mention it to the nurse responsible for them or the ward sister. You know the person and may be the first to pick up signs of change. A person’s condition may change as a response to different or new medication. Again, you should tell hospital staff what you have noticed and ask for it to be investigated.

If you have concerns about how someone is being treated and you do not think ward staff are responding to your concerns there are routes for you get help:

PALS (Patient Advice and Liaison Service)

has an office in Berkshire hospitals and can be contacted in person or by phone. They are not available at weekends.

- Prospect Park Hospital: 0118 960 5027
- Royal Berkshire Hospital: 0118 322 8338
- West Berkshire Community Hospital: 0118 982 2829
- Wokingham Community Hospital: 0800 064 3330

Email addresses for PALS are available on page 20 of the “Support” booklet.

Call 4 Concern is available at all times at Royal Berkshire Hospital for you to contact if you notice a serious change in a person’s health which you do not think is being treated properly by ward staff.

- Royal Berkshire Hospital: 07774 751 352



Preparing for difficult decisions

As you become the key decision-maker for someone with dementia, you may face some difficult decisions about their care. Some are discussed in this section and also in the “Legal and money matters” booklet.

If you are able to discuss future decision-making while the person is well enough it will help you to get a better understanding of their feelings and preferences. This can be upsetting for both them and you. It may help to involve someone else, such as other family members, a doctor, Memory Clinic nurse or support worker with experience of dementia care.

There may be times when you need to make a decision that would not be the person’s preference. This might be necessary to make sure they or other people (including you) are safe.

Below are some of the decisions that can be difficult for people. Everyone will face different decisions, depending on how the person they care for is affected by dementia and what their living arrangements are.

Decisions affecting where a person lives

Having someone else look after the person

The person you care for may want you to care for them all the time, but that isn’t always possible. If you are working or need a break or are not able to do everything for them (for example, lifting them) you will need to get help, so they can stay longer in their own home. This can be a carer who stays with the person at home or takes them out. If this doesn’t work well initially, you may need to try different approaches. It may be that the person simply didn’t like the particular carer who came, or the place they visited if they went out.

Making adjustments at home

Even small changes, such as installing grab rails in the bathroom and toilet can be upsetting for some people, as they are an outward sign of a person's illness and the change in their life. But they can be essential for safety. See "Adaptations at home" on page 8 of this booklet.

Some changes can be particularly upsetting; for example, moving someone's bedroom downstairs so they don't have to manage stairs; moving from a shared bedroom to separate rooms so that you can sleep better.

Moving someone from their current home

You may decide to move a relative to live with you, or to live in a house or flat that is easier for them to manage (such as sheltered accommodation) or, if they cannot be looked after at home, to a care home. All these decisions are difficult and likely to be upsetting for the person themselves. See "Making a new Home" on page 6 of this booklet.

Occasionally, if a person's symptoms are impossible to manage at home or in a care home, they may have to be moved, at least for a while, to a specialist hospital ward. Again, while this may be essential for safety it can be very upsetting. You should be able to talk with their psychiatrist about this decision and what it may mean for their long term care.

Moving someone from hospital to a care home or nursing home

People who have been in hospital usually look forward to coming home. You may be able to build a package of home care, with the help of Social Services and care agencies, so that a person can return home. But it may be a better decision to allow some time for recovery in a nursing home before making a further decision about whether they can return home. In this situation the hospital social work team will help to arrange a nursing or residential home for them to move to, at least initially.

Decisions about medical treatment

A person may have made decisions about the kind of treatment they want or do not want towards the end of their life. They may have given legally-binding instructions in an Advance Decision. For example, they may have said that if they have a cardiac arrest, medical teams should not attempt to resuscitate them. Preparing Advance Decisions is discussed in the booklet on "Legal and money matters", page 4.

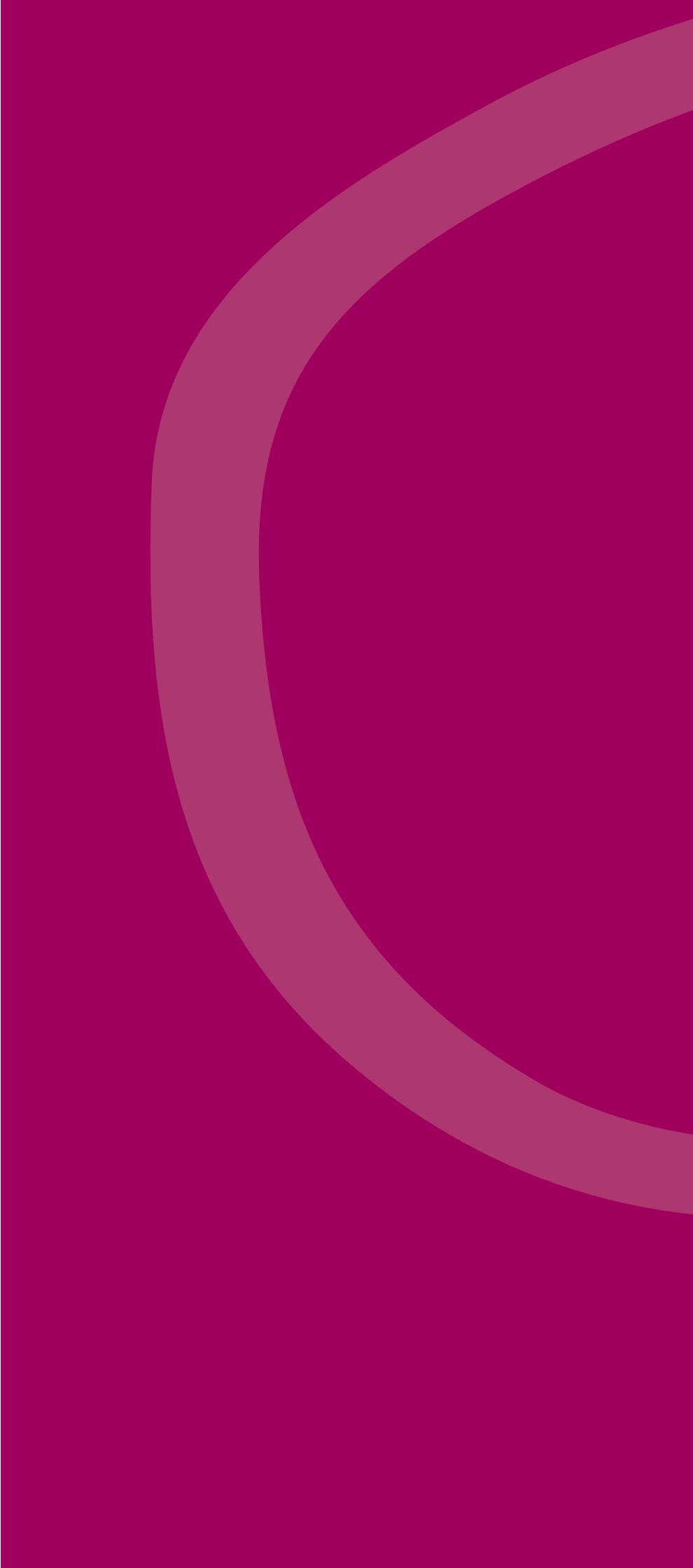
Decisions about end of life care are difficult. You may have to weigh up the benefits of treatments against how they might affect the quality of life of the person; for example, if they need to go into hospital for major surgery, rather than stay at home. It is important to remember that, whether it is decided to have treatment or not, the medical team caring for them will still do their best to ensure they are comfortable and free from pain. Refusing further medical treatment does not mean they will not be cared for.

Hospitals have specialists in the care of the elderly. They have wide experience of the decisions that people may face at the end of their lives. GPs are also trained to help patients consider the benefits and consequences of treatment. You should be able to get advice from hospital specialists or your GP about the consequences of deciding whether to accept or refuse treatment for the person you care for. They may suggest you involve nurses trained in palliative care. Palliative care is the care someone receives to keep them comfortable and supported towards the end of their life.

It may be that you need to make decisions on a person's behalf about the treatment they receive. You are able to do this if they have given you Lasting Power of Attorney for Health and Welfare (see the "Legal and money matters" booklet, page 2).

If you do not have Lasting Power of Attorney for Health and Welfare for the person you care for, you may need a Mental Capacity Assessment to confirm whether or not they are

able to make their own decisions about their treatment. The person's GP or solicitor can carry out the assessment for a fee, see page 3 of the "Legal and money matters" booklet.



Berkshire Healthcare NHS
Foundation Trust
Fitzwilliam House
Skimped Hill Lane
Bracknell
RG12 1BQ

Telephone: 0118 960 5027
www.berkshirehealthcare.nhs.uk

© Berkshire Healthcare NHS
Foundation Trust 2014.
All rights reserved.

Dementia handbook for carers

Berkshire West

A–Z of symptoms and behaviours

Dementia look-up guide **1**

Glossary **21**

Dementia look-up guide

This A–Z list describes many of the symptoms and behaviours that people with dementia experience. It gives tips for helping to make them more comfortable.

It's important to remember that there are different types of dementia, each with different symptoms, so not everything in this list will be relevant to the person you care for. Even for one type of dementia, not everyone will experience the same symptoms, or symptoms that are very mild for one person may be more severe for another. As you will hear many times, everyone with dementia is different.

The behaviour of someone with dementia is often driven by emotion. It can be easier to understand if you can try to put yourself in their shoes to find out what they may be feeling. Many of the tips recommended here are aimed at trying to help the person cope with what they are feeling. Often this can lead to positive changes in their behaviour.

The A–Z is intended as a quick guide to help you consider what might be underlying the symptom or behaviour, what you might be able to do to help the person you care for and where you can find more information, advice and support.

The list includes:



Tips for things you can try that may improve the person's comfort.



Signposts to further information, some of which is available on the web, in printed leaflets, or from organisations that support people with dementia and their carers.

Aggression Aggressive behaviour can be frightening and upsetting for you as a carer. It has many causes including:

- fear or suspicion
- frustration with a situation or environment
- low mood
- being in pain
- no other way of sharing feelings
- loss of judgement
- loss of inhibitions and self-control.

When a person with dementia behaves aggressively, it's important not to make the situation worse by arguing with them as this may make them lash out. It may help to leave the room for a short time. Remember that even if the aggression seems personal or intentional, it is usually the result of the condition.

When the person is calm, act normally towards them. They may forget the incident quickly, or feel awkward about it. Acting normally can help you both move on.



For more information:

Dealing with aggressive behaviour
www.alzheimers.org.uk/factsheet/509

Anxiety Dementia can make a person feel anxious because the changes they are experiencing make them feel out of control. They may be particularly anxious in new places or situations. Some medication can increase anxiety.

Anxiety has many symptoms. Not everybody experiences them all. Some of the more common symptoms are:

- worrying a lot
- feeling afraid that something bad might happen
- avoiding situations that feel difficult to cope with
- feeling tense or uptight
- sweating – not caused by heat
- dry mouth
- pounding or racing heart
- churning or “butterflies” in the stomach
- trembling or shaking
- feeling dizzy.

You may be able to reduce a person's anxiety by having a routine which is easy for them to follow. It may help to do things on specific days of the week and to tell the person what the plan is for each day; for example, “It's Monday, so I'll be going out for the afternoon and Jane will be here with you”.



Aggression tip:

Keep a note of anything that triggers aggressive behaviour. It may take some trial and error, but if you identify the triggers, you can avoid them.

If you think the aggression is linked to pain, contact your GP.

If a person is agitated and shouts out at night, try putting a night light in their room to make them feel less anxious.

If they are calling for someone from their past, try talking to them about this period in their life.



Anxiety tip:

Look for patterns that trigger anxiety so you can avoid them; for example, large groups of people or loud noises.

Help the person control mild anxiety through slow, steady breathing.

Try to reduce their coffee and alcohol intake; encourage regular exercise.

If you can, create distractions, for example, gardening or listening to music they enjoy.

Show them that you are concerned for them and reassure them.

[Continued on next page](#)



For more information:

[See Depression](#)

Depression and anxiety

www.alzheimers.org.uk/factsheet/444

Aphasia/dysphasia (problems with speech and language)

Many people with dementia have difficulties with speech and language. These may develop earlier in someone with Fronto-temporal dementia than other dementias but not everyone with Fronto-temporal dementia is affected. People with Alzheimer's and Vascular dementia may also have speech and language problems.

People may have different kinds of difficulties, including:

- problems recalling names or words
- hesitant, effortful speech
- stuttering
- sound errors in speech (e.g. "gat" for "cat")
- using the wrong word order or tense
- understanding conversation, reading and writing may also be affected.

Speech and language therapists who specialise in dementia can give advice on these problems and how to help the person communicate. Contact your Memory Clinic for an appointment.

Language changes may also be a side-effect of medication so you should check with your GP, especially if medication has been changed recently.

In the later stages of dementia, a person may stop speaking altogether but this doesn't mean their wishes and preferences can be ignored. Try to keep talking with them and, when you are doing things for them, ask for their preferences.



For more information:

[See Communication](#)

BUPA's Talking Toolkit

www.bupa.co.uk/individuals/health-information/dementia

Communication

www.alzheimers.org.uk/factsheet/500

Frontotemporal dementia

www.nhs.uk/conditions/frontotemporal-dementia/pages/introduction.aspx

What is frontotemporal dementia?

www.alzheimers.org.uk/factsheet/404



Aphasia/dysphasia

tip: To help someone communicate

- help them by saying a word they are trying to say
- ask simple yes/no questions based on what you think they might be trying to say
- give them time to respond to you rather than talking over them
- point to things you think they are talking about
- show you're listening by keeping eye contact.

Check that the person's dentures are comfortable.

If someone's ability to speak changes suddenly it could mean they have had a stroke. Use the **FAST** method to check

F is the person's Face drooping at one side or their smile uneven?

A is their Arm drooping?

S is their Speech slurred? Can they repeat simple sentences?

T Telephone 999 if they have these symptoms.

Balance [See Falls](#)

Bladder or Bowel problems See [Constipation, Incontinence](#)

Choking See [Eating and drinking](#)

Communication Dementia gradually affects the way a person communicates. Their ability to present ideas and reason clearly can change. Getting communication right is one of the most challenging parts of caring for someone with dementia and can have a big impact on their quality of life.

As a person's dementia progresses, they may find it hard to start conversations. You may have to get the conversation going.

The person may find it hard to say what they want. Avoid asking them to make complicated choices; keeping it simple will help. Try to rephrase what you say to make it easy for the person to respond, for example, rather than ask "would you like a drink?", try asking "I am having a cup of tea, would you like one too?" Remember to speak calmly and always make eye contact.

Try to look out for patterns or situations that seem to make understanding more difficult for the person; for example, in a noisy or busy environment, when rushing or trying to do several things at the same time, having a conversation whilst the television or radio is on in the background.

Having other people around, such as family or friends, can help get conversation going and the person you care for may enjoy listening even if they can't join in. It may help to have some photographs or a memory album nearby so that visitors have something to talk about. Joining Dementia Cafés or other activities can provide a friendly environment with people to talk to.



For more information:

See [Aphasia/dysphasia](#), [Decision Making](#)

BUPA's Talking Toolkit

www.bupa.co.uk/individuals/health-information/dementia

www.nhs.uk/conditions/dementia-guide/pages/dementia-and-communication.aspx

Communicating

www.alzheimers.org.uk/factsheet/500



Communication tip:

Remember to arrange regular hearing checks. If a person is struggling to hear they are unlikely to make conversation or reply to questions.

Contact your local Alzheimer's Society representative about joining Dementia Café meetings and other groups in your area.

See page 12 of the "Support" booklet for contact details.

Concentration People with dementia often find it difficult to carry out tasks and activities that require concentration and planning. They may find it hard to follow instructions. It is good to keep active and independent for as long as possible so try to encourage them to do things for themselves, even if it takes more time than you doing things for them.



For more information:

See, "Everyday activities" on page 18 in the "Day-to-day living" booklet.

Confusion There are many signs of confusion, such as getting lost in familiar environments, not knowing how to get out of a familiar room or not knowing whether it is night or day. Confusion can cause anxiety for a person with dementia and their carer. Try to be patient with them. It may help to avoid introducing too many new or different things.

Look out for patterns that make the person more confused, such as visiting new places or noisy environments, so that you can avoid them or prepare the person for the situation. However there may not always be a particular cause.

Confusion can be due to a bladder or chest infection, which can easily be treated with medication. If a person's confusion suddenly increases, is severe or if they are hallucinating or suspicious, contact your GP.



For more information:

See [Delirium, Memory](#)

Constipation Constipation can be common in people with dementia. It may be caused by not drinking enough fluids, or reducing or changing the kind of food they eat (particularly eating less fibre), or becoming less mobile. It can cause discomfort, distress and, in extreme cases, can lead to incontinence.

Try to prevent constipation by ensuring the person you care for drinks plenty of fluids and has some fibre in their diet, such as wholemeal bread, fruit and vegetables.

A person may try to reduce the amount they drink if they suffer from bladder incontinence: they may worry that they may not be able to control their bladder. You may need to explain to them why it is important for them to drink and give them drinks during the morning so they are less likely to need the toilet at night.

If you think someone is constipated, and fluids and diet don't improve things, consult your GP as laxatives may be required.



For more information:

See [Incontinence](#)



Concentration tip:

Try to be patient and help them get started on an activity, giving gentle reminders about next steps as they progress.

Focus on what the person can do rather than what they can't.



Confusion tip:

Showing pictures, memorabilia or talking about fond memories may help a person remember people or places they have forgotten.

Confusion can be due to an infection. If you think this might be the cause, contact your GP.



Constipation tip:

If a person seems to be avoiding fluids, remember that soups, fruit salads, vegetables, jelly and many other foods contain fluids, which can boost their intake (and can be a good source of fibre, too).

Co-ordination Some types of dementia may lead to co-ordination problems. This means a person cannot manage controlled movements, for example, when eating meals or dressing.

A Community Care Assessment from your Social Services will be helpful for advice and to see if aids can be put in place to help with specific tasks. See the section on Community Care Assessments, on page 3 of the “Day-to-day living” booklet. For Social Services contact details, see page 4 of the “Support” booklet.



For more information:

Dressing

www.alzheimers.org.uk/factsheet/510

Eating and drinking

www.alzheimers.org.uk/factsheet/511

Decision making Making decisions can become increasingly difficult for people with dementia. They may become anxious if they are faced with too many decisions or questions to answer. It is good for someone to make their own decisions for as long as possible so try to be patient and repeat the choices they have.

If a person is beginning to struggle with important decisions check they have all their legal arrangements in place; for example, that they have an up-to-date will and have made arrangements for Lasting Power of Attorney. See page 2 of the “Legal and Money Matters” booklet.



For more information:

[See Communication](#)

Delirium Delirium is sometimes called an “acute confusional state”. It can prevent a person from concentrating or thinking clearly, and may make them unaware of their surroundings. People with delirium can often see or hear things that are not actually there, but which seem very real to them (hallucinations). It is usually temporary and stops when treated.

Delirium develops very quickly, it may be as a result of infection, constipation or medication. It often happens in hospital due to change in environment or after surgery, sometimes due to the anaesthetics, infection or pain.

If you suspect signs of delirium tell hospital staff immediately, as delaying treatment can increase the risk of other complications. If the person you care for is at home contact the GP immediately.



Co-ordination tip:

Keep meals simple; meat and fish without bones. Cut food into small pieces if the person can't do it themselves. They may prefer just a fork or a spoon rather than a knife and fork. Don't over fill cups, to reduce spills.

To help with dressing ensure clothes are not inside out and have buttons and zips already undone. Think about getting shoes without laces or buckles.



Decision making tip:

Try to state the outcome of a decision, to give context, for example, “Would you like to wear a jumper today as it's cold?”. It may help to show the person the options; for example, laying two outfits out.

Limiting choices can prevent overwhelming a person; for example, “Would you like ice cream or cake?” rather than “What would you like to eat?”.



Delirium tip:

Certain kinds of infections, such as a bladder or chest infection, can cause delirium. Contact your GP if you suspect signs of infection, and collect a urine sample if possible.

If the person has had two or more infections one after the other, the GP may refer them for further investigation.

[Continued on next page](#)



For more information:

[See Hallucinations, Infections](#)

Unusual behaviour

www.alzheimers.org.uk/factsheet/525

Sight, perception and hallucinations in dementia

www.alzheimers.org.uk/factsheet/527

Urinary tract infection (UTI) and dementia

www.alzheimers.org.uk/factsheet/528

Denial [See Lack of insight](#)

Depression Depression may occur along with the development of dementia or as a result of receiving a dementia diagnosis. It can show itself in many different ways.

Psychological symptoms include:

- continuous low mood or sadness, feeling hopeless and helpless
- having no motivation or interest in things
- finding it difficult to make decisions
- feeling anxious or worried
- having suicidal thoughts or thoughts of self-harm.

Physical symptoms include:

- moving or speaking more slowly than usual
- change in appetite or weight
- unexplained aches and pains
- disturbed sleep.

Social symptoms include:

- taking part in fewer social activities and avoiding contact with friends
- having difficulties in home and family life.

If a person has some of these symptoms every day for more than two weeks, ask for help from your GP or Memory Clinic.



For more information:

[See Anxiety, Emotions, Mood swings](#)

Depression and anxiety

www.alzheimers.org.uk/factsheet/444

Disorientation [See Confusion](#)

Dysphasia [See Aphasia](#)



Depression tip:

Make it clear to the person that you care for them and are concerned for them. Suggest simple activities together that may relieve their symptoms, such as a gentle walk or watching a film together.

Caring for someone with dementia can also lead you to become depressed. It is important to keep yourself as well as you can, both mentally and physically. So if you experience persistent symptoms, you should consult your GP.

Eating and drinking A person with dementia may find eating and drinking difficult for a range of reasons. They may not recognise the food in front of them, they may find it hard to use a knife and fork or to chew or swallow food.

Some people may be at risk of choking because they have difficulty swallowing. However they may also refuse help to eat.

While it's common for people with dementia to have difficulty eating, others may overeat or not eat a balanced diet. They may not know when they are satisfied or may not remember what they have eaten or having eaten at all. It may be up to you to ensure they eat a healthy range of foods.

Ensuring a person drinks enough fluid is as important as making sure they eat well. If they don't drink enough dehydration can increase the chance of constipation and bladder or urinary tract infections. Make sure they have a regular supply of non-alcoholic drinks (water, fruit juices).

Helping manage a person's food and drinking needs to be balanced with remembering that food is a source of pleasure and comfort. While you may be anxious about their eating and drinking, it is wise to avoid letting it become a tense experience.

Speech and language therapists specialise in helping people who have difficulty swallowing so if you are concerned you should contact your Memory Clinic for help.



For more information:

[See Co-ordination](#)

Eating and drinking

www.alzheimers.org.uk/factsheet/511

NHS choices nutrition guide

www.nhs.uk/Conditions/dementia-guide

Emotions There are many reasons why a person with dementia may become more emotional than they have been previously. The initial diagnosis of dementia is likely to upset them and may make them feel low or frightened. They may feel angry that they have been affected or that their life will become limited.

They may also respond emotionally to situations they would have previously found easy to deal with; for example, if they find they cannot do things they used to be able to do independently. If they rely heavily on you as their carer they may become upset if you are not there; if you go out they may forget where you are.

Usually these emotions will pass but if a person's mood stays continuously low, or they remain very agitated, you will need to consult their GP or Memory Clinic.



Eating and drinking

tip: Make things easier by serving food you know the person enjoys. Serve small, manageable portions with cutlery they find easy to use.

Using crockery which is plain and contrasts with the tablecloth can help to define the edge of the plate.

If the person lives on their own you can try preparing food in packs labelled according to days of the week and times of day.

Regular exercise and fresh air help to increase the appetite.

Remember to arrange regular dentist and optician check-ups. Toothache, uncomfortable dentures or impaired vision could detract from eating.



Emotions tip:

Sharing your experience with others may help you deal with strong emotional demands from the person you care for. Memory Clinic teams and people from support organisations may be able to help you deal with your reaction to difficult and emotional situations.

[Continued on next page](#)

Sometimes dementia can also limit the emotions people express, so they seem to become cold and detached, and may say hurtful things. All these can be upsetting for you as a carer but try to remember that the person is not being hurtful intentionally.



For more information:

See also [Anxiety](#), [Depression](#), [Lack of Insight](#), [Mood swings](#)

Falls People with dementia are at risk of falls because their sense of balance and ability to react quickly may be reduced, along with their memory and judgement. Changes to medication or having an infection can be linked to falls.

Stress and confusion can also increase the chances of a fall, as can problems with vision.

It's worth taking simple steps to help the person navigate their home more easily and safely. This may involve having a Community Care Assessment, which can be arranged through Social Services, see page 3 of the "Day-to-day Living" booklet. If you change the layout of their home to make it safer, try not to make major changes rapidly as this can be upsetting, see "Adaptations at home" on page 8 of the "Day-to-day living" booklet.



For more information:

See [Mobility](#), [Vision](#)

Safety in the home

www.alzheimers.org.uk/factsheet/503

Equipment, adaptations and improvements to the home

www.alzheimers.org.uk/factsheet/429

www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/home-environment.aspx

For information on assistive technologies (helpful aids around the home) www.atdementia.org.uk

Hallucinations A hallucination is the experience of perceiving something that isn't there; for example, seeing people who are not there. Hallucinations can occur with some types of dementia, particularly Dementia with Lewy bodies, Parkinson's disease dementia, and sometimes with Alzheimer's disease.

Hallucinations may occur if someone has delirium or they may be a response to some medications. Hallucinations can be visual but a person may also hear sounds or feel sensations that are not there. They will believe that what they are experiencing is real and, in some cases, may be frightened by it.

Hallucinations differ from everyday misperceptions, which some people with dementia experience, where they misinterpret



Falls tip:

Don't forget to make sure the person has regular eye tests and is wearing the correct glasses.

Encourage them to wear fitted, supportive shoes rather than slippers.

If you are concerned about falls, speak to your GP, Social Services or Memory Clinic to organise a visit from an Occupational Therapist.

See page 4 of the "Support" booklet for Social Services contact information.



Hallucinations tip:

Rather than cause conflict by contradicting someone who is hallucinating, reassure them that you are there with them. Listen to what they are experiencing and try to talk with them about it and, if they are upset, ask what is worrying them.

[Continued on next page](#)

everyday objects. For example, they may think that a curtain, a coat on a peg or a shape in a hedge is a person, or that people on TV are real. Everyday misinterpretations are not hallucinations.

If full hallucinations last a long time and upset the person you care for, and particularly if they include sound and touch as well as vision, tell your GP. It may be that altering their medication can help them.



For more information:

[See Misperceptions](#)

Sight, perception and hallucinations in dementia
www.alzheimers.org.uk/factsheet/527

Hearing Communication problems caused by dementia will be made worse if a person cannot hear well. They may be more likely to “turn off” from conversations, so they miss the stimulation of other people’s company.

If you think the person you care for has difficulty in hearing, contact your GP for a hearing test. It may be that a simple build up of ear wax is affecting them or they may need a hearing aid.

If they already wear a hearing aid you may need to remind them to wear it and help them use it properly.



For more information:

[See Communication](#)

Hygiene Some people with dementia may neglect hygiene and may need persuasion to wash and bathe. They may have difficulties with washing and bathing because they are at risk of falls in the bathroom or shower.

In both cases a carer may need to be involved with helping the person. This can be difficult since washing is usually a private activity, so it can be hard for a person to adjust to having help. Try to approach it in a practical and sensitive way so that it does not become an uncomfortable experience.

If the person you care for has limited mobility or has problems balancing, make sure that:

- the floor is dry and not slippery
- locks are removed from the door
- you are aware of your own safety when you are bending and helping with lifting.



For more information:

Washing and bathing
www.alzheimers.org.uk/factsheet/504

Check whether the person needs glasses, or whether the glasses they have are the right prescription.

Some visual difficulties can be caused by eye problems associated with age, such as cataracts, glaucoma or macular degeneration. If you think they may have eye problems arrange an opticians appointment for them.



Hearing tip:

Remember to arrange regular hearing checks.

To get the most out of a hearing aid:

- clean it and keep it in good working order
- check the battery regularly
- adjust it for different situations.



Hygiene tip:

Use visual cues before you start, for example, carry a towel and let the person smell the soap. They may be less likely to refuse to bathe if it’s clear what is expected.

To help make the experience of bathing or showering positive:

- explain what’s happening as you go along
- check the water temperature
- make sure the bathroom is warm on cool days
- use pleasant-smelling shampoo and bubble bath.

Incontinence Incontinence can be difficult to deal with, and upsetting both for the person you care for and for you. There are a range of different causes of incontinence in people with dementia. They may lose control over their bowel or bladder, or may not be able to empty their bladder properly or have an infection. They may simply forget to go to the toilet, or where the toilet is. They may also have lost the ability to tell when they need the toilet.

When someone is incontinent it's important to be understanding, retain a sense of humour and remember that it's not their fault. You may also want to try the following:

- put a sign on the toilet door, such as a photo of the toilet
- keep the toilet door open, with a light on and make sure that the person you care for can get to it easily
- make sure they can remove their clothes – some people with dementia can struggle with buttons and zips
- look out for signs that they need to go to the toilet, such as fidgeting and standing up/sitting down
- get adaptations to the toilet, such as grab rails or a raised seat, if necessary, to make using the toilet easier. Social Services may supply these if you ask for a Community Care assessment
- have a routine and remind them to follow it; for example, visiting the toilet at regular intervals and before going to bed
- avoid caffeinated drinks particularly in the evenings.



For more information:

Coping with incontinence
www.alzheimers.org.uk/factsheet/502

Infections A person with dementia may not recognise the early signs of an infection; for example, that they need to pass water more frequently or that it is painful, or that their chest feels tight. So you may need to monitor them carefully.

A first sign of infection in a person with dementia can be a fall, a sudden, increased level of confusion, or a sudden lack of interest in what is going on around them. It's easy to think these are connected with their dementia rather than caused by infection. If you notice these symptoms you should ask the GP to check that they don't have an infection.

An infection that goes unnoticed could quickly become serious and result in the person needing to go to hospital which can be very disorienting for someone with dementia.



For more information:

See [Confusion](#), [Delirium](#), [Falls](#), [Hallucinations](#)



Incontinence tip:

If the person you care for is having problems with incontinence, ask your GP to refer them to a continence advisor who can advise on things like waterproof bedding or incontinence pads.

Remember that incontinence could also be due to bladder or urinary tract infection or a side effect of medication and should be checked by your GP.



Infections tip:

If the person you care for suffers from frequent bladder infections, keep a supply of urine sample bottles so that you can get a sample to their GP quickly for testing.

If a person has had two or more courses of antibiotics they might need further investigation.

Prostate problems in men, prolapse of the womb in women, or constipation could contribute to problems with continence.

Lack of inhibition The changes to the brain that come with dementia can mean that some people lose their inhibitions and say or do things they would not have done in the past. They may, for example, make personal comments about other people, or strike up conversations with strangers.

Lack of inhibition can cause difficulties. A person may become too trusting of strangers and so, especially if they live alone, be vulnerable. They may not realise that if they talk with children they don't know, other adults may become concerned for the children's safety.

Lack of inhibition can also lead to other changes; for example, a person may take other people's property or shoplift. There may be changes in their sexual behaviour, or they may say things that are very sexual in conversation.

Many people with dementia will not have any of these changes, but if the person you care for does you may need help and advice, both to protect the person and, sometimes, for your own and others' protection, too. You do need to get advice from your GP or Memory Clinic.

Lack of inhibition can be an early sign of Fronto-temporal dementia.



For more information:
[See Sexual behaviour](#)

Lack of insight (Denial) Some people with dementia do not have insight into their own condition and will not admit that they have any health problem or, more specifically, that they have dementia. This is particularly common with Fronto-temporal dementia but can also occur with other dementias.

Lack of insight can be difficult to deal with. It may have made it difficult to get a diagnosis in the first place. Even after diagnosis a person may not accept that there is anything wrong and may get angry if you suggest there is.

If someone lacks insight into their condition it may lead to difficult or dangerous situations, if they will not accept help or use aids such as walking frames, or believe they are still safe to drive.

If the person you care for lacks insight you will often need diplomacy and persuasion skills to help them. Try to avoid confrontation. There may be situations where you have to take action to keep someone safe. For example, making sure they cannot get access to car keys, or go out on their own.

If a person's lack of insight becomes very difficult to deal with you will need to seek help from your Memory Clinic.



Lack of inhibition

tip: Remember that when a person's behaviour changes, it is not within their control. So rather than blame them, try to get help to manage the situation.

Try not to be too embarrassed to get help. Most professionals will have experience of others with similar problems.

If the behaviour of the person has changed it is a good idea to mention this to visitors, so that they are not upset by the changes.



Lack of insight tip:

If you have a confrontation with the person because they lack insight, try to move on and get back to normal quickly afterwards. They will not be able to recognise that they are wrong and proving it will only distress them.

Try to reassure someone after a confrontation by showing that you care for them.

Language See [Aphasia/Dysphasia, Communication](#)

Memory Loss of memory is one of the early signs of some forms of dementia. It is often mistaken for the forgetfulness that can develop as people age. For a person with dementia it is more extreme, and they may not realise how forgetful they are.

People with dementia find it difficult to learn new things, so may not remember arrangements or new people or places. As dementia advances, some people may seem to be living in the past. They may focus on things they can remember rather than new events that are happening around them. So, for example, if the person you care for has moved home, they may forget where they are and refer to the home they had before moving. In advanced dementia they may not recognise even familiar environments, including their own home.

Memory loss is particularly evident in Alzheimer's and Vascular dementia. It may not be a problem for people with Frontotemporal dementia or Dementia with Lewy bodies, at least in the early stages of the condition.

Your Memory Clinic may run cognitive stimulation courses to help people with early stage dementia by stimulating their memory, problem-solving skills and language ability. This does not cure or slow down dementia, but can bring some improvements in symptoms.

Using prompts or memory aids can help supplement a person's failing memory.



For more information:

[See Confusion, Repetitiveness](#)

See "Adaptations at home, Memory aids" on page 8 of the "Day-to-day living" booklet

Coping with memory loss

www.alzheimers.org.uk/factsheet/526

Misperceptions Some people with dementia may misinterpret everyday objects; for example, they may think that a curtain or a coat on a peg is a person or that people on TV are real. Everyday misinterpretations can usually be reduced by moving the object that the person is misinterpreting, or having more light in a room.



For more information:

[See Hallucinations](#)

Sight, perception and hallucinations in dementia

www.alzheimers.org.uk/factsheet/527



Memory tip:

Memory loss can lead to repetitive behaviours (such as asking the same question, or repeatedly checking the same thing). The person may have no memory of having done the same before. Rather than reminding them, it is better to try to distract them by moving on to a new conversation or changing activity.

If distraction doesn't work try to focus on how they feel, for example asking, "Is that worrying you?", or turn the conversation to talking about whatever they are focussing on.



Misperceptions tip:

Check whether the person needs glasses, or whether the glasses they have are the right prescription. Some visual difficulties can be caused by eye problems associated with old age, such as macular degeneration, glaucoma or cataracts.

Mobility There are many conditions associated with ageing that can either restrict mobility or affect balance, for example, arthritis, strokes, heart conditions, infections, medication side effects. If a person lacks concentration or coordination due to dementia, these problems may be made worse.

If the person you care for develops mobility problems, contact their GP to discuss possible causes. It is important to encourage a person to keep mobile, as this helps to maintain muscle strength.

They may need a walking stick or frame. A Community Care Assessment from your Social Services will suggest what sort of aid may be helpful. An assessment may also recommend physiotherapy to improve mobility. If you need help to move a person (for example, so that they can shower or have a bath) an assessment may make recommendations for what help is needed.

Remember that if someone is using a walking stick or frame you may need to rearrange furniture to give them space to move safely.



For more information:

[See Co-ordination, Falls](#)

Moving and walking about

www.alzheimers.org.uk/factsheet/501

Walking aids

www.dlf.org.uk/factsheets/walking

Mood swings People with dementia can experience mood swings. Their mood may dip as they think about their diagnosis and what it means for their future. They may feel scared and frustrated as they find they cannot do things they had been able to do previously or cannot understand what is going on around them. Changes in their ability to control their feelings and in their ability to say what is wrong, may mean they express their feelings much more strongly than in the past.

If a person expresses their feelings violently, and you feel you are at risk, you must tell their GP or Memory Clinic.

Looking after a person with dementia can be demanding and carers and other family members may also experience strong mood changes. These feelings are normal and it is better not to bottle them up but to talk to someone about worries. This could be a family member or friend, someone from your local dementia support group or your GP, who can refer you to a counsellor in your area or you can talk to your Memory Clinic.



For more information:

[See Anxiety, Depression, Emotions, Lack of inhibition](#)

www.nhs.uk/Conditions/stress-anxiety-depression/Pages/low-mood-stress-anxiety.aspx



Mobility tip:

Try to keep the person you care for mobile for as long as you can but allow plenty of time for activities. Do not hurry them as feeling stressed can increase the chances of a fall.



Mood swings tip:

If you notice the person you care for gets frustrated by not being able to do something in particular, try to help them with it, without making a fuss. So, for example, help them to get dressed as though it was normal routine.

Night walking Getting up and walking either around the house or the neighbourhood at night can be hazardous for a person with dementia, exhausting for a carer living with them, and a worry if the person lives alone. A person with dementia may wake for many reasons but then not realise that it is night rather than day and so not consider the risks of either walking around a dark house, or going out.

Night walking can be a result of a person waking from a vivid dream. This could have been caused by medication taken in the evenings, or they may be in pain (for example, caused by arthritis). Talk to their GP or Memory Clinic to see if it is possible to change the time of day for medication that might be causing dreams or to check if the person might need pain relief.

Some types of assistive technology (for example, pressure mats with alarms that are triggered if a person has got out of bed) may help a carer sleep, knowing they will be woken if the person gets up.



For more information:

See [Pain, Sleep disturbance, Wandering](#)

Assistive technology

www.dlf.org.uk/factsheets/telecare

Pain A person with dementia may be in pain but may not be able to tell you about it. Or they may be able to say they are in pain but not where it is. This can lead to irritability and difficulty sleeping, which can increase their confusion.

They may have conditions that are causing them pain such as arthritis, poor circulation or leg ulcers. They may have had falls that they have not mentioned. In some cases it is possible they have fallen and cracked or broken a bone. They may be in pain because they have an infection, or are suffering from constipation or indigestion.

It is important to look out for signs of pain. If you notice cuts, bruises or inflammation, have them checked by their GP and possibly at your hospital Accident and Emergency department. If a person seems to be in pain when eating you might ask their GP to check whether they have any problems with their mouth or digestion.

Some medication can cause indigestion or stomach cramps so talk to the GP if you think this might be a cause.

Continuous pain can lead to people becoming less mobile. Talk with the GP about whether they might be helped by regular pain relief.



For more information:

See, "Pain" on page 25 in the "Day-to-day living" booklet



Night walking tip:

If a person is struggling to sleep at night, stop caffeine or alcoholic drinks in the evening. Stopping daytime napping may also help.

You may also need to monitor what television programmes a person watches before bedtime in case they are watching things that keep them awake.

Try to ensure the person has some form of exercise during the day so that they are more physically tired and relaxed at night.



Pain tip:

Look out for signs of pain, such as moving in a new and awkward way, wincing when touched in a particular place, trying to protect a part of their body when washing or dressing.

If the GP prescribes pain relief, ensure it is given at regular intervals to prevent pain, rather than waiting until the person seems to be feeling pain.

Passiveness (lack of interest) Sometimes people with dementia can appear withdrawn or uninterested in people and events around them. This behaviour could be a result of not being able to recognise people or places, or of not being able to plan and initiate tasks or conversation independently.

Some people may stop activities they were skilled at in the past, for example, music or art, because they realise they can't achieve the same standards they used to. Try to encourage them to continue or keep their interest; for example, by going to a concert, listening to music or visiting a gallery and looking through art books.

Low mood can also cause a person to become less responsive. If you think that the person you care for might be depressed, it is important to ask for advice from your GP or Memory Clinic.



For more information:

[See Depression](#)

See "Everyday activities at home" on page 18 of the "Day-to-day living" section.

Personality changes Dementia can make people feel anxious, lost, confused and frustrated. Although each person with dementia handles these kinds of feelings in their own way certain changes in personality and/or behaviour are common, for example:

- repeating questions or doing something repeatedly
- walking and pacing up and down
- aggression, irritability, shouting, using foul language or saying things that are not appropriate. This is called "verbal disinhibition".
- losing inhibitions in their behaviour, including sexual behaviour
- becoming very withdrawn
- becoming suspicious of other people.

It can be distressing for carers to see such changes in a person they know well. When these behaviours are stressful to deal with it's important to remember that the person is not being difficult deliberately.



For more information:

[See Aggression, Depression, Emotions, Lack of inhibition](#)

Unusual behaviour

www.alzheimers.org.uk/factsheet/525



Passiveness tip:

Check that the person has not become withdrawn because they cannot hear or see properly. Regular hearing and eye tests will help eliminate these problems.

You may be able to help a person get involved in hobbies or tasks if you break them down into simple steps and prompt any steps that may have been forgotten.



Personality

changes tip: Occasionally a change in behaviour can be due to a change in medication. This could be starting a new medication or changing the dose or stopping a current one. If you see a change following a new prescription, contact your GP or Memory Clinic.

Repetitiveness People with dementia can repeat questions or carry out certain actions over and over again. A common behaviour is repeated phone calls to the same relative or friend. Or they may want to investigate something to see how it works, even if they knew this in the past. This repetitiveness may be due to memory loss or boredom, anxiety or side effects of medication.

Carers can find this repetitiveness hard to deal with but need to remember that the person may have no recollection of saying or doing something before and that it can be upsetting to be told they are being repetitive.

As far as possible it is best to try to distract the person, moving them on to a new topic or activity. Involving other people in caring for the person can be particularly helpful if they are repetitive.



For more information:

Unusual behaviour
www.alzheimers.org.uk/factsheet/525

Restlessness Restlessness could be a response to something that is irritating a person; for example, they are too hot, or they don't like the TV or radio being on. They may be bothered by things that haven't upset them in the past, or that do not bother others. Restlessness may also be a response to boredom, hunger or thirst, needing to go to the toilet, feeling unwell, being in pain or a need for exercise.

If the person can tell you what is bothering them, try to remove the cause. If you can't find a cause try reassuring them and introducing different activities to distract them.



For more information:

[See Anxiety, Wandering](#)



Repetitiveness tip:

It can be useful to have a range of activities in mind that could help prevent boredom; for example, helping with something round the house, looking at a favourite magazine, book or photographs, listening to music.



Restlessness tip:

If there are activities a person can do with you (for example, helping in the house or garden) it may reduce their restlessness.



Sexual behaviour

tip: Talk to the GP or Memory Clinic if you are worried about a person's sexual behaviour.

The Alzheimer's Society also have a helpline for confidential advice
0300 222 11 22.

Sexual behaviour As with other aspects of personality, a person's sexual feelings can change when they have dementia. Depending on how they have been affected, a person may experience:

- more, less, or no interest in sex
- their ability to perform sexually may change
- a change in inhibitions – they may be less sensitive to other people's feelings and to what behaviour is acceptable to others.

Some couples find it easy to adapt to these changes. But sometimes the changes can bring feelings of loss, anger or embarrassment. This is often the case if the person becomes more interested in sex than they have been in the past and is very demanding of their partner, makes advances to other people, or masturbates in public.

It is important to ask for advice if the behaviour of the person has changed in a way that may put them at risk if their behaviour is very public or is putting pressure on you through increased demand for sex.



For more information:

[See Lack of inhibition](#)

Sex and dementia

www.alzheimers.org.uk/factsheet/514

Sleep disturbance People with dementia often experience disturbed sleep. They may wake during the night or be restless. When they wake they may not know whether it's night or day and so may want to get up.

Sleep disturbance is a result of the brain losing the control it usually has over how alert or drowsy people are at different times of day. It may also be a result of the person being in pain with arthritis or other problems. Some medication can also cause drowsiness during the day, interfering with sleep at night; other medication can make people more alert at night.

It is worth talking with the GP about whether the person's medication could be affecting their sleep patterns, or whether they need pain relief that will help them sleep better. However, it helps to be aware that sleep medication increases the risk of falls so caution is advised.



For more information:

[See Night walking, Pain](#)



Sleep disturbance

tip: If getting to sleep seems to be the problem it may help to avoid naps during the day by keeping busy, so that the person is tired at bed time.

Keep to regular bedtimes and avoid alcohol or caffeine at night.

Suspicion of others Dementia can make people become suspicious of others. This can be a result of their difficulty understanding what is going on around them. Their assumption may be that other people are conspiring against them and holding information back. They may not recognise familiar faces and so believe that people they know should not be in their home. This behaviour may seem delusional but these feelings will seem very real to the person with dementia.

They may not remember where they have put things and may accuse other people of taking their possessions. If they lose items, they may panic and convince themselves that they have been burgled. They may start hunting for things in a very frenzied way. It may be difficult to reassure them unless you can find the thing they have lost.

If possible, try to reassure them. Check with them, to make sure that their anxieties do not have any foundation. Keep lighting bright to help improve the person's ability to recognise people and things.



For more information:

[See Anxiety, Depression, Personality change](#)

Swallowing [See Eating and drinking](#)

Vision Some people with dementia can have problems interpreting what they see; for example, they might interpret a folded blanket as someone lying on a bed, or people on television as real, small people in their room. They may misinterpret patterns and reflections or shadows as holes to fall into or as things to trip over.



For more information:

[See Falls, Hallucinations, Misperceptions](#)

Sight, perception and hallucinations in dementia
www.alzheimers.org.uk/factsheet/527



Suspicion tip:

Keep things in predictable places to help the person you care for find them.

Check that a person's difficulty recognising people isn't being made worse by poor eye sight. Make sure they have regular check ups.



Vision tip:

Make sure that rooms are well lit. Avoid patterned carpets and rugs, especially on stairs.

Make sure the person has regular eye tests and wears the correct glasses.

Wandering Walking or pacing is a common behaviour in people with dementia. They may pace up and down or leave their home for long walks. They may set out to go somewhere but then forget where they're going and become disorientated and lost. This is distressing and potentially risky for the person, and can cause their carer anxiety.

If the person you care for is likely to wander, try to stay aware of where they are. You may be able to use assistive technology to alert you if the door of the house has been opened; similarly there are devices that can alert you if the person moves beyond a certain distance from their house. If it is safe to do so, try engaging them in activities that include walking, for example, sweeping up leaves.

Make sure a person who is likely to wander has a contact phone number for a carer or neighbour with them. Put contact information on a plastic key fob or wallet attached to keys and place within a handbag or coat pocket. Do not put the person's own address on their key fob or wallet as this could make them vulnerable if they were to lose them.



For more information:

[See Nightwalking](#)



Wandering tip:

If you are concerned that the person you care for will be unable to find their way home you can let trusted, local shopkeepers and neighbours know. Ask them to contact you if they're concerned about the person's behaviour.

Glossary

The list of terms below might be used in letters from the Memory Clinic or hospital to your GP.

Affect Expression of emotion or feelings

Ataxia Lack of muscle co-ordination (e.g. problems with walking)

Atrophy Decrease in size or wasting of a body organ (e.g. brain in dementia)

B12 Type of water soluble vitamin essential for brain and nerve function

BADLS or BADLS+ (sometimes ADLS) Measure of person's ability to look after themselves (Bristol Activities of Daily Living scale)

bd To be taken twice daily (medicine)

BP Blood pressure

BPSD Behavioural and psychological symptoms of dementia (e.g. agitation, low mood, hallucinations in dementia)

Bradycardia Slow heart rate

CDT Clock drawing test

Cerebrovascular Relating to blood vessels within the brain

Cognition Mental processes including thinking, concentrating, remembering

CST Cognitive Stimulation Therapy – structured sessions of activities for people with dementia

Delirium Severe confusion that can develop over hours or days, due to physical illness such as urine infection. May cause hallucinations

Dysphagia Swallowing difficulties

Dysphasia/aphasia Impaired communication due to problems in the brain

ECG Heart tracing test that records heart activity (printed out on pink paper)

Euthymic Person's mood is normal (not depressed)

Executive function Ability to plan and complete a sequence of events

FBC Full blood count – blood test which includes check for anaemia

Folate A type of water soluble vitamin essential for brain and nerve function

Frontal Relating to the front part of the brain

Glu Glucose – blood test checking sugar level

Hallucination Experience of perceiving something that is not there (e.g. seeing animals that are not there, hearing voices when no one is talking)

Involucional change Decrease in size (similar to atrophy)

Ischaemic Inadequate blood supply to an organ

LFTs Liver function tests – blood test checking how well the liver is working

mane Morning (e.g. medicine to be given in morning)

Mild cognitive impairment (MCI) Mild cognitive problems that aren't severe enough to be dementia

MMSE Mini Mental State Examination – a standard test of cognition

MOCA Montreal Cognitive Assessment – a test of cognition

Neuropsychological or neuropsychometric assessment Detailed cognitive testing that can help with making a diagnosis. Carried out by a psychologist or specialist speech therapist

nocte Night-time (e.g. medicine to be given at night)

Occipital Relating to the lobe at the back of the brain

od Once daily (medicine)

Parietal Relating to the lobe at the top of the brain

Psychosis Set of experiences including hallucinations or delusions that make the person struggle to understand reality

QOF dementia register Quality and Outcomes Framework (QOF) – a system where GP surgeries keep registers of patients with conditions such as dementia to ensure follow up

REM sleep behaviour disorder Sleep disturbance where person has vivid dreams and may shout out or be physically active

Renal Relating to the kidneys

Respite Time out for the carer (e.g. the person with dementia going to a day centre or into a care home for a short period)

Small vessel disease Changes to very small blood vessels in the brain resulting in brain tissue damage from lack of oxygen

Temporal Relating to the lobes on the sides of the brain

tds Three times per day (medicine)

TFTs Thyroid function tests – blood test checking how well the thyroid gland is working

TIA Transient ischaemic attack. Sometimes called a mini-stroke. When blood supply to part of the brain is temporarily disrupted

qds Four times per day (medicine)

U+Es Urea and electrolytes – blood test checking how well the kidney is working

UTI Urinary tract infection



Berkshire Healthcare NHS
Foundation Trust
Fitzwilliam House
Skimped Hill Lane
Bracknell
RG12 1BQ

Telephone: 0118 960 5027
www.berkshirehealthcare.nhs.uk

© Berkshire Healthcare NHS
Foundation Trust 2014.
All rights reserved.

Dementia handbook for carers

Berkshire West

Support

Finding the support you need **1**

Guide to who's who **2**

Health and Social Services **4**

Local support services **5**

Transport **11**

Activities **12**

National organisations **15**

Financial support **17**

Assistive technology **18**

Care quality and safety **19**

Finding the support you need

This booklet has two sections:

- a “Who’s who” of the types of medical and community professionals who are involved in the care of people with dementia
- a list of contact information for local and national organisations that may be able to give you information and help.

The Who’s who guide should help explain how different types of organisations work together and guide you to the right kind of contact if you have a query or concern. Support organisations work closely with one another so, if they are not able to help you themselves, they may direct you to the right organisation for your enquiry.

The list of contact information does not include every organisation in the area. Small groups that people have set up to meet a very specific need may not be included. It is likely that larger, local organisations will be able to put you in touch with them.

Note that contact details for organisations may change over time. If you are having problems contacting an organisation listed here, you may need to check with Directory Enquiries or on the web. Local support organisations such as Age UK, Alzheimer’s Society or Berkshire Carers will also have up-to-date information.

If you are contacting any of these services regularly it may help to write their details on the “Contacts” page within “Record Keeping”.

 **Tip:** The lists of contact information include website addresses (URLs) for some organisations. These can be very long to type but if you go to the organisations’ home page you may be able to search for the information you need.

Guide to who's who

Understanding the services and support that is available from different organisations, and how they connect, will help you find and manage support for the person you care for.

Who to contact for healthcare, support and funding

NHS	Community organisations	Social Services	Department for Work and Pensions
Medical care, referral and treatment	Community care support, help to access funding	Community care services and funding	Allowances and benefits
<ul style="list-style-type: none"> Your GP Hospital clinics and wards Memory Clinic and Community mental health services Accident and Emergency 	Voluntary organisations such as: <ul style="list-style-type: none"> Age UK Alzheimer's Society Berkshire Carers Carers UK Crossroads 	Social Services (local authority) provide services for: <ul style="list-style-type: none"> Parking and transport Council Tax relief Care services Home adaptations 	The Department for Work and Pensions (DWP) provides: <ul style="list-style-type: none"> Allowances Benefits Pensions
<p>Your GP is the route to NHS hospital and clinic services, apart from emergencies. Hospitals and clinics will feed back to your GP.</p>	<p>Support organisations and charities provide direct care services and help carers find out about other services. They can advise on applying for funding and benefits.</p>	<p>Social services assess and make recommendations for your care needs and provide some support services. Some services are free but you may be charged for others.</p>	<p>DWP gives allowances, benefits and pensions to some people with dementia and their carers. You have to apply for these and may need to re-apply if your needs change.</p>

Medical care, referral and treatment

Your GP

A GP is responsible for the health of their patients at home and sees them for all health problems. A GP may refer patients to specialist doctors for diagnosis and treatment, and receives reports and advice about treatments from specialists.

District Nurses

District Nurses are an essential part of later stage home care. They visit patients at home to help treat physical symptoms, such as pressure sores and continence problems. They can help to access additional medical care and support. GPs or other medical professionals may refer you to your local District Nursing team.

NHS hospital clinics and wards

Hospitals provide specialist medical care that is not provided by a GP. A person may be referred to hospital by their GP, moved from Accident and Emergency (A&E) to hospital wards, or be given appointments by A&E to come back to a clinic. There is specialist mental health care in general hospitals to support people with dementia.

Accident and Emergency (A&E)

Hospital A&E departments give urgent and immediate care. A person may be referred to A&E by their GP, out-of-hours GP or other medical service; or they may call an ambulance, or come to the hospital independently.

NHS Memory Clinic and Community Mental Health Team

Psychiatrists

Doctors based at Memory Clinics who may make home visits. Also available in general hospitals to support patients with dementia. They help with diagnosis and may prescribe medication.

Clinic and community mental health nurses

Specialist dementia care nurses who support patients with complex needs. They advise on day-to-day care and comfort, and suggest other services that provide support.

Nurse prescribers

Nurses who specialise in dementia medication. They may prescribe medicines (instead of the psychiatrist), adjusting medicine dosage at follow up appointments.

Occupational therapists (OT)

Work with Memory Clinics and hospitals to assess needs of people with dementia at home and recommend equipment to help with memory and mobility. May carry out Community Care and Carers' Assessments for Social Services. May also give more general advice or suggest other services and support to help a patient.

Speech and language therapists

Specialists in communication problems and difficulties with eating or swallowing. May also be involved in diagnosing type of dementia and give general advice.

Clinical psychologists

Develop and run treatment courses for people with dementia, such as cognitive stimulation therapy (CST). They treat patients and carers with problems, such as anxiety and depression. May also be involved in diagnosing dementia.

Community care support and help to access funding for care

Voluntary organisations such as Age UK, Alzheimer's Society, Berkshire Carers and Crossroads provide community care. They often work in partnership with the Community Mental Health Team and Social Services. Their support ranges from respite care at home to day centres and activities. They may help you apply for funding.

Community care services and funding

Social Services (local authority) carry out Community Care and Carers' Assessments to find out what support you need. They provide support, such as day centres, respite care, care homes and transport and parking schemes. They fund personal budgets to help pay for care, if you are eligible. They are obliged to provide advice about services whether or not you are eligible for funding.

Allowances and benefits

Department for Work and Pensions (DWP) may provide some funding, including Attendance Allowance and Carers' Allowance, pensions and other benefits. Some local community organisations can help you make your applications.

Lasting Power of Attorney

Contact and conversations about care are easier if the person you care for has granted you Lasting Power of Attorney (LPA). See the booklet "Legal and money matters", page 2.

Health and Social Services

Medical dementia care

Memory services in Berkshire West are made up of three Memory Clinics: in Reading, Newbury and Wokingham. At these clinics you may see a variety of specialists including doctors, nurses, occupational therapists, psychologists and speech and language therapists.

Reading

Hazelwood Memory Service
Prospect Park Hospital
Honey End Lane
Reading RG30 4EJ

- Telephone: 0118 960 5959

Newbury

Beechcroft Memory Clinic
West Berkshire Community Hospital
Hillcroft House
Rookes Way
Thatcham RG18 3HR

- Telephone: 01635 292 070

Wokingham

Wokingham Memory Clinic
Barkham Day Hospital
Wokingham Community Hospital
Barkham Road
Wokingham RG41 2RE

- Telephone: 0118 949 5101

Royal Berkshire Hospital

There are specialists in dementia care in the Older People's Mental Health Liaison Team, which is based in the hospital.

Older People's Mental Health Liaison Team

Royal Berkshire Hospital
London Road
Reading RG1 5AN

- Telephone: 0118 322 8320

Community care

Your local Social Services can help to work out what additional services and support people with dementia and their carers need. Everyone is entitled to an assessment of their needs. Social Services are also required to provide information and advice about care support to anyone in their local area.

Reading Adult Contact Team (ReACT)

- Telephone: 0118 937 3747
- Email: communitycare@reading.gov.uk
- Website: www.reading.gov.uk/residents/care-and-support-for-adults

West Berkshire Adult Social Services (Newbury)

- Telephone: 01635 503 050
- Email: ccenquiries@westberks.gov.uk
- Website: www.westberks.gov.uk/scip

Wokingham Adult Community Care

- Telephone: 0118 974 6772
- Email: wokinghamdirect@wokingham.gov.uk
- Website: www.wokingham.gov.uk/socialcare

Social Services Emergency Duty Service (Across Berkshire)

For contact outside of office hours in an emergency

- Telephone: 01344 786 543

Local support services

Dementia Care Advisory Service

Advice and support for people with dementia and their carers. Liaison between the NHS and community services.

For people over 65 with dementia and their carers

Reading:

- Telephone: 0118 959 6482
- Email: moira.hemson@alzheimers.org.uk

West Berkshire

- Telephone: 01635 500 869 or 07713 390 712
- Email: kim.westall@alzheimers.org.uk

Wokingham:

- Telephone: 0118 969 9428
- Email: susan.patterson@wokingham.gov.uk

For people under 65 with dementia in West Berkshire, Reading and Wokingham

- Telephone: 0118 949 5101 or 07919 396 355
- Email: gill.stokes@wokingham.gov.uk

SHaRON

SHaRON is a secure social networking service for relatives and carers of people with mental health conditions including dementia. The service is managed by Berkshire Healthcare medical staff. It is free of charge.

For an invitation to register ask a health professional, or at your Memory Clinic.

General advice services

Citizens Advice Bureau

Citizens Advice Bureau (Reading)

Minister Street
Reading RG1 2JB

- Advice line telephone: 0845 071 6379
- Website: www.readingcab.org.uk

Information for people with disabilities, their carers and over 60s

- Telephone: 0845 071 6380

Citizens Advice Bureau (West Berkshire)

2nd Floor, Broadway House
4–8 The Broadway
Northbrook Street
Newbury RG14 1BA

- Telephone: 0844 477 9980
- Website: www.westberkscab.org.uk

Citizens Advice Bureau (Wokingham & District)

Suite 2 (1st floor)
26–28 Market Place
Wokingham RG40 1AP

- Telephone: 0844 499 4126
- Email: public@wokingham-cab.org.uk
- Website: www.wokingham-cab.org.uk

CommuniCare

A Christian organisation which helps people in Reading by offering information, advice and support. Can provide legal advice and help with form filling.

- Telephone: 0118 926 3941
- Email: office@communicare.org.uk
- Website: www.communicare.org.uk

Nquire

Information, advice and support on a range of areas including benefits advice, debt referrals, letter writing and befriending service for people in the west of Reading.

- Telephone: 0118 959 8558
- Email: admin@nquire.org
- Website: nquireadvice.org.uk

Reading Community Welfare Rights Unit

Independent and confidential legal advice about welfare benefits, debt and housing.

- Telephone: 0118 955 1070
- Email: advisor@readingspecialist.co.uk
- Website: www.readingcommunitywelfarerightsunit.co.uk

Information and advice about care and care support

A key source of information for carers of people with dementia are courses run by Memory Clinics. Contact your local clinic for more information, see page 4 of this booklet. Listed below are other organisations that can provide information and support.

Age Concern

Age Concern Newbury & District

Provide a number of services at the Fair Close Day Centre in Newbury. They also provide a meals on wheels service.

- Telephone: 01635 41294
- Website: www.fairclosedaycentre.org.uk

Age Concern Twyford & District

Run a day centre open on week days in Twyford.

- Telephone: 0118 934 4040
- Email: info@ageconcerntwyford.org.uk
- Website: www.ageconcerntwyford.org.uk

Age Concern Woodley

Provide specialised support for people with dementia including day services, overnight respite service, lunches and Alzheimer's café at the Southlake Centre. The Centre also hosts a younger people with dementia day service.

- Telephone: 0118 969 1471
- Email: debbie.heffernan@ageconcernwoodley.org.uk
- Website: www.ageconcernwoodley.org.uk

Age UK

Information, advice and local services for people over 50. There are a number of local Age UK services across Berkshire

- National Helpline: 0800 169 6565
- Website: www.ageuk.org.uk

Age UK Berkshire

Information, advice and a range of services, including financial advocacy, befriending, shopping services, community support, home from hospital. Details of services for your area can be found on the website or by calling Age UK.

- Telephone: 0118 959 4242
- Website: www.ageuk.org.uk/berkshire

Age UK Berkshire also provide one-to-one support for people with dementia or memory loss in West Berkshire and West Reading.

- Telephone: 0118 959 4242
- Email: info@ageukberkshire.org.uk
- Website: www.ageuk.org.uk/berkshire

Age UK Home from hospital service

Provide support, practical advice and reassurance, free of charge, to anyone who has received treatment in hospital and is worried about how to manage at home.

- Telephone: 0118 959 4242
- Email: info@ageukberkshire.org.uk
- Website: www.ageuk.org.uk/berkshire/our-services/home-from-hospital

Age UK Reading

Information and advice service. Also local services including lunch clubs, toe nail cutting and befriending for people over 50.

- Telephone: 0118 950 2480
- Website: www.ageuk.org.uk/reading

Alzheimer's Society

Provide information and support. Local services include dementia support, befriending service and activity groups such as Singing for the Brain and Dementia Cafés.

- National helpline: 0300 222 1122
- Website: www.alzheimers.org.uk

Local Offices

- Reading
Telephone: 0118 957 1183
- East Berkshire (Wokingham area)
Telephone: 01628 626 331
- West Berkshire (Newbury area)
Telephone: 01635 500 869

Berkshire Carers Service

Local information and support for carers. They can help with form filling, give advice on benefits and grants, and on health and social care services. They provide emotional support and run a number of carer support groups in the area.

- Telephone: 0800 988 5462
- Email: helpline@berkshirecarers.org
- Website: www.berkshirecarers.org

Carers Trust (Formerly Crossroads and Princess Royal Trust for Carers)

National organisation for information and advice to carers. They can point you to local support services.

- Telephone: 0844 800 4361
- Website: www.carers.org

Crossroads – Reading and Wokingham

Provide a carers' respite service, where a trained support worker can take over some of your caring responsibilities. Also provide a 24

hour emergency "back up" service if you are unable to care in an emergency. You need to register in advance for this service.

Crossroads Care Reading

- Telephone: 0118 945 4209
- Email: reading@crossroads.org.uk
- Website: www.readingcrossroads.org

Crossroads Care Oxfordshire and West Berkshire (Newbury and District)

- Telephone: 01635 30008
- Website: www.oxfordshirecrossroads.org.uk

Crossroads Care Wokingham

- Telephone: 0118 979 5324
- Website: www.wokinghamcrossroads.org

Crossroads Emergency Out-of-hours Helpline

24 hour emergency "back up" if you are unable to care due to illness or a family emergency. You need to register in advance for this service.

Newbury and District

- Telephone: 07867 673 063

Reading and Wokingham

- 0118 945 4218

Dementia UK – Admiral Nursing Direct

Admiral Nurses are specialist dementia nurses who provide support families affected by dementia.

- Admiral Nurse Direct helpline: 0845 257 9406
- Email: direct@dementiauk.org
- Website: www.dementiauk.org

Admiral Nurse for Younger People with Dementia

Provides specialist support to the carers and families of younger people with dementia.

- Telephone: 0118 949 5101
- Email: rikki.lorenti@ypwd.info

Optalis

A Wokingham Council appointed business that provides free advice about care and care services in the Wokingham area.

- Telephone: 0118 908 8420
- Email: info@optalis.org
- Website: www.optalis.org

Parkinson's UK

Information and support through a national helpline and local support.

- National helpline: 0808 800 0303
- Website: www.parkinsons.org.uk

Local Offices

There are branches of Parkinson's UK in Reading, Bracknell and Slough. For all local enquiries:

- Telephone: 0844 225 3674
- Email: bvso.south@parkinsons.org.uk

For younger people with Parkinson's disease

- Reading Positively Enthusiastic Parkies (PEPS) has a website: www.pdpeps.org

Younger People With Dementia (Berkshire West)

Provide information and organise events for younger people with dementia.

- Email: contact@ypwd.info
- Website: www.ypwd.info

Day care services

Reading

Charles Clore Court Activity Centre

Provide a full programme of activities for people with dementia, two days a week.

- Telephone: 0118 950 7914
- Email: activitiesteam@a2dominion.co.uk

The Maples Resource Centre (previously Phoenix Day Services)

Provide day care services to older people and people with dementia who need support to help maintain their independence.

- Telephone: 0118 901 5364
- Email: vanessa.hart@reading.gov.uk

West Berkshire

Hungerford Resource Centre

Services for the elderly or people with dementia and those with learning or physical disabilities.

- Telephone: 01488 682 601
- Email: hungerfordresourcecentre@westberks.gov.uk
- Website: www.westberks.gov.uk

Greenfield House Resource Centre

Day services for adults with learning disabilities, physical disabilities and those with dementia.

- Telephone: 0118 943 2074
- Email: greenfieldhouserresourcecentre@westberks.gov.uk
- Website: www.westberks.gov.uk/index.aspx?articleid=2005

The Phoenix Resource Centre

Day services for adults with learning or physical disabilities, and those with frailty and dementia.

- Telephone: 01635 520 150
- Email: phoenixresourcecentre@westberks.gov.uk
- Website: info.westberks.gov.uk/index.aspx?articleid=29672

Carnation Day Care Services

Day services for older people and people with dementia.

- Telephone: 07880 617 365
- Email: gloriabund@btinternet.com

Tanzanite Day Services, Theale

Day care service for people with physical disabilities, head injury, Parkinson's disease and neurological conditions (including dementia).

- Telephone: 0118 962 2498 or 07708 626 533
- Email: tdservice@live.com

Wokingham

COATS Woodmancote Centre

Provide a range of services including lunch.

- Telephone: 01344 773 464
- Email: secretary@coatscrowthorne.org.uk

Age Concern Southlake Crescent, Woodley

Provide day services, lunches and Alzheimer's café. The Centre also hosts a younger people with dementia day service.

- Telephone: 0118 969 1471
- Email: debbie.heffernan@ageconcernwoodley.org.uk
- Website www.ageconcernwoodley.org.uk

Age Concern, The Twyford Centre

Provide a range of services and respite care.

- Telephone: 0118 934 4040
- Email: info@ageconcerntwyford.org.uk
- Website www.ageconcerntwyford.org.uk

Pinehaven Day Service (Optalis)

Provide a range of activities, entertainment and refreshments for older people.

- Telephone: 0118 908 8411
- Website: optalis.org

The Link Visiting Scheme

A friendship service for elderly people who are on their own or can't get out and about.

- Telephone: 0118 979 8019
- Email: office@linkvisiting.org
- Website: linkvisiting.org

WADE Day Centre

Provide a range of activities including lunch for members (age 60 plus) and their guests.

- Telephone 0118 978 7025
- Website: wadecentre.co.uk

Younger people's service

Hazelwood Social Day Care Club for younger people with dementia

Day services for people of working age who have a diagnosis of dementia. The club offers two days a week, one day for people with higher care needs.

- Telephone: 0118 945 4209
- Email: maryjacobs@readingcrossroads.org
- Website: www.readingcrossroads.org

Meal delivery services

The person you care for may be eligible for Meals on Wheels, provided by their local Social Services. The services listed below are businesses that charge for meal delivery.

Apetito

Hot meal delivery service.

- Telephone: 01225 809 166
- Email: info@apetito.co.uk
- Website: www.apetito.co.uk

Dining in @ home

Provide a frozen meals delivery service.

- Telephone: 01903 820 057
- Email: niall@sussexfarmhousemeals.co.uk

Oak House Foods

Frozen meals and grocery delivery service.

- Telephone: 0118 975 6565
- Email: reading@oakhousefoods.co.uk
- Website: www.oakhousefoods.co.uk

Wiltshire Farm Foods

Frozen meals delivery service.

- Telephone: 01635 298 044
- National helpline: 0800 773 773 (24 hour)
- Email: newbury@wiltshirefarmfoods.com
- Website: www.wiltshirefarmfoods.com

Other helpful organisations

Aster Living

Provide practical services including minor electrical and plumbing work, repairs and home security. Can also carry out home adaptations.

- Telephone: 0333 400 8299
- Email: handihelp@asterliving.co.uk
- Website: www.asterliving.co.uk

Berkshire Fire and Rescue Service

Free home safety checks, including making an escape plan, advice on action to be taken in the event of a fire and fitting smoke alarms.

- Telephone: 0118 932 2734
- Email: community.safety@rbfrs.co.uk
- Website: www.rbfrs.co.uk

British Red Cross – Home from hospital care

Help following a stay in hospital to provide extra support and care at home.

- Telephone: 0844 412 2750
- Website: www.redcross.org.uk/what-we-do/health-and-social-care/independent-living/support-at-home

Forestcare Lifeline Alarms

Bracknell Council's emergency response service. Provide and monitor Lifeline alarms in the community and in sheltered housing.

- Telephone: 01344 786 500
- Email: forest.care@bracknell-forest.gov.uk
- Website: www.bracknell-forest.gov.uk/forestcare

Radar National Key Scheme

A Radar key opens locked public toilets, for example in shopping centres, parks, bus and train stations. Radar keys can be bought on-line from Disability Rights UK.

- Website: crm.disabilityrightsuk.org/radar-nks-key

Talking Therapies

NHS therapy service which helps people with anxiety, depression or stress. Any adult living in Reading, Wokingham or West Berkshire can ask for an assessment to see if these therapies are appropriate.

- Telephone: 0118 976 9121
- Email: talkingtherapies@berkshire.nhs.uk
- Website: www.talkingtherapies.berkshire.nhs.uk

The Silver Line

The Silver Line is a free and confidential helpline which provides information, friendship and advice to older people. Open 24 hours throughout the year.

- Telephone: 0800 470 8090
- Website: www.thesilverline.org.uk

Transport

Local authority transport

Handybus: West Berkshire

Transport for older people and people with disabilities in the West Berkshire area.

Basildon / Beenham / Bradfield / Pangbourne / Purley / Streatley / Theale

- Telephone: 0118 930 4837

Burghfield / Mortimer

- Telephone: 0118 983 6611

Chieveley / Compton / Downlands

- Telephone: 01635 202 519

Hungerford

- Telephone: 01488 683 727

Newbury

- Telephone: 01635 37111

Thatcham

- Telephone: 01635 874 666

Keep Mobile: Wokingham

Transport for older people (70 plus) and people with disabilities in the Wokingham area.

Wokingham

- Telephone: 0845 544 0850
- Email: admin@keepmobile.org.uk
- Website: www.keepmobile.org.uk

ReadiBus: Reading, Wokingham

Transport for people with restricted mobility in the Reading and Wokingham area.

Reading and Wokingham

- Telephone: 0118 931 0000
- Website: www.readibus.co.uk

Voluntary driver schemes

Voluntary driver service to take people to and from medical and dental appointments.

Bracknell Forest

- Telephone: 01344 383 515

Caversham Good Neighbours

- Telephone: 0118 948 3466 (call weekdays between 9.30am and 11.30am)

Earley

- Telephone: 0118 966 6234

Shinfield

- Telephone: 0118 988 3400

Twyford, Wargrave and district

- Telephone: 0118 934 3010

Wokingham

- Telephone: 0118 978 2446

Woodley

- Telephone: 0118 969 8849

West Berkshire

- See website for local phone numbers: www.volunteerwestberks.org.uk/handybus.htm

Blue Badge parking scheme

Parking Scheme for people with disabilities. Can be used in your own car or in taxis. Apply by contacting your Social Services.

Reading

- Telephone: 0118 937 2033

West Berkshire (Newbury)

- Telephone: 01635 503 276

Wokingham

- Telephone: 0118 974 6800

Activities

Local activities

Listed below are some popular local activities. New groups are set up regularly so you may like to contact your Dementia Care Advisor for more ideas that suit your interests.

Exercise and social activities

Age UK Active Living

Provide a wide range of activities for people over 50, including tai chi, seated yoga and zumba, photography walks and therapeutic gardening. Some activities are more physically demanding than others. To find out what activities are suitable call or check their website.

- Telephone: 0118 959 4242
- Email: info@ageukberkshire.org.uk
- Website: www.ageuk.org.uk/berkshire/our-services/activities-events

Alzheimer's Society activities

Activities include Dementia Cafés, Gardening for the Brain, Singing for the Brain, Stay Sharp! and yoga. Contact your local Society office or see their web page.

- Website: www.alzheimers.org.uk

Local Offices

- Reading Telephone: 0118 957 1183
- East Berkshire (Wokingham area)
Telephone: 01628 626 331
- West Berkshire (Newbury area)
Telephone: 01635 500 869

Dementia empowerment groups

Empowerment groups bring together people with dementia and their carers who seek to change policies and services that affect them. They are coordinated by the Dementia Engagement & Empowerment Project (DEEP).

- DEEP website: dementivoices.org.uk

West of Berkshire Empowerment Group

- Telephone: 0118 959 6482
- Email: moira.hemson@alzheimers.org.uk

Gardening projects

Five a Day market garden

Community activities at Englefield nursery, near Theale. Some activities aimed at older people.

- Telephone: Pam Goddard 0793 967 6050
- Email: pam@fiveaday.org.uk
- Website: www.fiveaday.org.uk

Ridgeline Trust

Gardening project in Reading running a range of groups for people with disabilities.

- Telephone: Graham Johnson 0118 926 1790
- Email: ridgeline@hotmail.com
- Website: www.ridgeline.org.uk

Thrive

Gardening project for people with disabilities at Trunkwell Garden, Beech Hill, near Reading.

- Telephone: Sue Tabor 0118 988 4844
- Email: trunkwell@thrive.org.uk
- Website: www.thrive.org.uk/trunkwell-garden-project.aspx

Reminiscence activities

Many of the dementia cafés in Berkshire run activities based on reminiscence. There are also collections of reminiscence materials at local museums.

Reading Museum

- Telephone: 0118 937 3400
- Email: education@readingmuseum.org.uk
- Website: www.readingmuseum.org.uk/get-involved/reminiscence

West Berkshire – Newbury Library

- Telephone: 01635 519 827
- Email: sedwards@westberks.gov.uk
- Website: www.westberks.gov.uk/index.aspx?articleid=22449

Dementia research

Thames Valley DeNDRoN

NHS research into dementia is coordinated by DeNDRoN (Dementias and Neurodegenerative Diseases Research Network). If you sign up to DeNDRoN you may be invited to participate in research to understand the causes of dementia and develop treatments for it. This research may bring long term benefit to others who are diagnosed with dementia.

- Telephone: 01865 234 310
- Email: help.research@nhs.net
- Website: www.dendron.nihr.ac.uk/thames-valley/discover-thames-valley-lrn

National activity support

Active Minds

Provide activity products to help people with dementia and Alzheimer's disease enjoy life.

- Telephone: 0207 688 6636
- Email: info@active-minds.co.uk
- Website: www.active-minds.co.uk

Age Exchange

Activities and resources for older people based on reminiscences.

- Telephone: 0208 318 9105
- Email: administrator@age-exchange.org.uk
- Website: www.age-exchange.org.uk

Robert Opie Collection

Provide activities for reminiscence, based on a collection of British advertising imagery and nostalgia.

- Telephone: 0800 018 8844
- Website: www.robertopiecollection.com

Specialist holiday providers

The following companies specialise in holidays for people with dementia and their carers. Other companies may also be able to help with holiday plans if you tell them about your requirements.

British Legion

Provide holiday breaks for ex-service personnel and their carers and families at special holiday centres. You need to apply and they will assess your needs before offering a holiday.

- Telephone: 0845 725 725
- Website: www.britishlegion.org.uk/can-we-help/care-and-support/breaks

Buchanhaven Holidays

Holidays in the Orkney Islands catered for the individual needs of people with dementia and their partner/carer.

- Telephone: 01856 874 093 or 0775 933 0892
- Email: mbuchan77@btinternet.com
- Website: www.buchanhavenholidaysorkney.co.uk

Vitalise

A national charity providing short breaks and holidays for people with dementia and physical disabilities, and their carers.

- Telephone: 0303 303 0145
- Website: www.vitalise.org.uk

Dementia Adventure

Provide breaks for people with dementia and their carers.

- Telephone: 01245 230 661
- Email: info@dementiaadventure.co.uk
- Website: www.dementiaadventure.co.uk

The Mede

A bungalow in Topsham, Devon, suitable for a person with dementia and their carer.

- Email: sallie.rutledge@yahoo.co.uk
- Telephone: 01392 421 189 or 07718 976 072
- Website: www.themedede.org

National organisations

Advice and support organisations

Age UK

Information, advice and local services for people over 50. There are a number of local Age UK services across Berkshire.

- National Helpline: 0800 169 6565
- Website: www.ageuk.org.uk

Alzheimer's Society

Information and support for people with all forms of dementia, their carers, family and friends. Also provide local services including dementia support, befriending service and activity groups.

- National helpline: 0300 222 1122
- Website: www.alzheimers.org.uk

Carers UK

Campaigning organisation that provides advice and support for a range of issues affecting carers, including legal and money matters.

- Helpline: 0808 808 7777
- Email info@carersuk.org
- Website www.carersuk.org

Dementia UK – Admiral Nursing Direct

Admiral Nurses are specialist dementia nurses who support families affected by dementia.

- Admiral Nurse Direct helpline: 0845 257 9406
- Email: direct@dementiauk.org
- Website: www.dementiauk.org

Parkinson's UK

Provide information and support through a national helpline and local support.

- National helpline: 0808 800 0303
- Website: www.parkinsons.org.uk

Frontotemporal support group

For carers of people with Frontotemporal dementia. The group meets several times a year.

- Email: frontotemp@aol.com
- Website: www.ftdsg.org

Lewy Body Society

Fund research into Dementia with Lewy Bodies (DLB). Their website provides information about the condition.

- Telephone: 0131 473 2385
- Website: lewybody.org

Posterior Cortical Atrophy (PCA) support group

Website provides information and support to people with PCA, and their families.

- Website: www.ucl.ac.uk/drc/pcasupport

Forces help

British Legion

Practical care, advice and support to the armed forces. They have a number of care homes and a visiting service.

- Telephone: 0808 802 8080
- Website: www.britishlegion.org.uk

Royal Air Force Association

Welfare support to the RAF Family which includes RAF veterans and their relatives.

- Telephone: 0800 018 2361
- Website: www.rafa.org.uk

Soldiers' and Sailors' Families Association (SSAFA).

Practical support and assistance to servicemen and women, veterans, and their families.

- Telephone: 0800 731 4880
- Website: www.ssafa.org.uk

Financial support

Department for Work and Pensions (DWP)

Pension Service

General enquiries about state pension eligibility, claims and payments.

For enquiries

- Telephone: 0800 731 7898

For a change of address, bank details etc.

- Telephone: 0845 606 0265
 - Website: www.gov.uk/contact-pension-service
-

Disability Benefits Centre

Advice and information about current claims.

- Disability Living Allowance (DLA)
Helpline: 0845 712 3456
 - Email: dcpu.customer-services@dwp.gsi.gov.uk
 - Website: www.gov.uk/disability-benefits-helpline
-

Attendance Allowance (AA)

Provides help to people aged over 65 who have disabilities.

- Helpline: 0845 712 3456
 - Email: attendance.allowanceenquiries@dwp.gsi.gov.uk
-

Personal Independence Payment (PIP)

Provides help with the cost of long-term ill-health or disability for people aged 16–64.

- Helpline: 0845 850 3322
-

Carer's Allowance

Information on Carer's Allowance and how to make a claim.

- Telephone: 0345 608 4321
- Email: cau.customer-services@dwp.gsi.gov.uk
- Website: www.gov.uk/carers-allowance-unit

Advice lines

CareAware UK – Elderly Care Funding Advice

Provide free information and advice, specialising in care funding advice for older people.

- Telephone: 0161 707 1107
 - Email: enquiries@careaware.co.uk
 - Website: www.careaware.co.uk
-

Carers UK

Free advice and support for legal and money matters.

- Helpline: 0808 808 7777
 - Email: info@carersuk.org
 - Website: www.carersuk.org
-

Firststop

Free advice to older people, their family and carers on housing, finance and all aspects of care.

- Phone: 0800 377 7070
 - Email: info@firststopadvice.org.uk
 - Website: www.firststopcareadvice.org.uk
-

Independent Age

Free advice and information on social care, benefits, care options and funding issues associated with longer term care. They also provide a befriending scheme.

- Advice line: 0800 319 6789
- Email: advice@independentage.org
- Website: www.independentage.org

Assistive technology

AlzProducts

Provide products that have been selected to help people living with dementia.

- Telephone: 0247 642 2224
- Website: www.alzproducts.co.uk

Aster Living

Personal alarms and sensors for safety.

- Telephone: 0333 400 8299
- Email: info@asterliving.co.uk
- Website: www.asterliving.co.uk

AT Dementia

Assistive technology designed for people with dementia and their carers.

- Telephone: 0116 257 5017
- Email: info@trentdsdc.org.uk
- Website: www.atdementia.org.uk

The Keysafe Company

Police approved key safes.

- Telephone: 01905 770 333
- Email: sales@keysafe.co.uk
- Website: keysafe.co.uk

Living made easy

Practical advice on daily living equipment.

- Helpline: 0300 999 0004
- Website: www.livingmadeeasy.org.uk

Nottingham Rehab Supplies

Provide a range of mobility products, disability aids and equipment. They also offer a product advisory service.

- Telephone: 0845 805 2236
- Email: customerservice@nrs-uk.co.uk
- Website: www.nrs-uk.co.uk

Pivotell

Reminders and medication dispensers.

- Telephone: 01799 550 979
- Email: office@pivotell.co.uk
- Website: www.pivotell.co.uk

Tunstall

Telecare products and services.

- Telephone: 01977 661 234
- Email: enquiries@tunstall.com
- Website: www.tunstall.co.uk

Care quality and safety

Advice lines

Action on Elder Abuse

Information, advice and support to people who have experienced or witnessed abuse.

- Telephone: 0808 808 8141
- Website: www.elderabuse.org.uk

Care Choices

Offer information and advice about arranging care and support services. Produce countywide care directories that include details of home care, residential and nursing care homes. These directories can be downloaded from their website or ordered by telephone.

- Telephone: 0800 389 2077
- Website: www.carechoices.co.uk

Care Quality Commission

Check whether the services you receive (e.g. hospitals, care homes, GPs, dentists and services in your home) meet national standards. You can read their inspection reports or report a concern.

If you need to report a concern:

- Telephone: 0300 061 6161
- Email: enquiries@cqc.org.uk
- Website: www.cqc.org.uk

Citizens Advice Bureau

Free, independent and confidential advice to help people to resolve problems.

- Website: www.adviceguide.org.uk

See local contact details under “Local support services” on page 5 of this booklet.

The National Care Line

Information about care and support for older people, their carers and families.

- Helpline 0800 069 9784
- Email: office@thenationalcareline.org
- Website: www.thenationalcareline.org

Samaritans

National and local confidential telephone service.

- Telephone: 08457 909 090
- Email: jo@samaritans.org

NHS and Social Services complaints and feedback

Local Clinical Commissioning Group (CCG)

NHS Newbury and District CCG

- Telephone: 0118 950 3094

NHS North & West Reading CCG

- Telephone: 0118 950 3094

NHS South Reading CCG

- Telephone: 0300 343 5722

NHS Wokingham CCG

- Telephone: 0118 929 9469

NHS Complaints Advocacy Service – SEAP

Support and advice in case of NHS complaints.

- Telephone
Reading: 0300 343 5722
West Berkshire: 0300 343 5731
Wokingham: 0300 343 5735
- Email: berkshire@seap.org.uk
- Website: www.seap.org.uk

Patient Advice and Liaison Service (PALS)

Advice and support to patients, families and carers to resolve problems and concerns about NHS services.

Berkshire Healthcare

- Telephone: 0118 960 5027
- Email: bht@berkshire.nhs.uk
- Website: www.berkshirehealthcare.nhs.uk

Royal Berkshire Hospital

- Telephone: 0118 322 8338
- Email: talktous@royalberkshire.nhs.uk
- Website: www.royalberkshire.nhs.uk

South Central Ambulance Service Trust

- Telephone: 01962 898 052
- Email: pals@scas.nhs.uk
- Website: www.southcentralambulance.nhs.uk

Healthwatch

Support, advice or help to raise an issue or complaint about health services.

Reading

Healthwatch Reading, Highbridge House, 16–18 Duke Street, Reading RG1 4RU

- Telephone: 0118 902 3912
- Website: healthwatchreading.org.uk

West Berkshire

Healthwatch West Berkshire, Hawkhurst House Headley Road East, Woodley, Reading RG5 4SN

- Telephone: 01635 886 210
- Website: www.healthwatchwestberkshire.co.uk

Wokingham

Healthwatch Wokingham, Suite 2 (1st floor), 26–28 Market Place, Wokingham RG40 1AP

- Telephone: 0118 418 1418
- Website: www.healthwatchwokingham.co.uk

Social Services Feedback

Reading

- Telephone: 0118 937 2905
- Email: complaints@reading.gov.uk
- Website: www.reading.gov.uk/a-to-z/c/complaints-adult-social-care

West Berkshire

- Telephone: 01635 503 391
- Email: complaintsadultsocialcare@westberks.gov.uk
- Website: www.westberks.gov.uk/complaintsaboutcare

Wokingham

- Telephone: 0118 974 6800
- Email: adultdisabilitydutydesk@wokingham.gov.uk
- Website: www.wokingham.gov.uk/socialcare/wokingham/contact/socialcare

Call 4 Concern

Available at all times at Royal Berkshire Hospital if you notice a serious change in a person's health which you believe is not being treated properly by ward staff.

- Royal Berkshire Hospital
Telephone: 07774 751 352

Emergency and urgent care services

Emergency services

- If you need the ambulance service, fire service or police assistance in an emergency call "999".

Urgent medical care

- If you need medical help fast but it's not an emergency, call "111".



Berkshire Healthcare NHS
Foundation Trust
Fitzwilliam House
Skimped Hill Lane
Bracknell
RG12 1BQ

Telephone: 0118 960 5027
www.berkshirehealthcare.nhs.uk

© Berkshire Healthcare NHS
Foundation Trust 2014.
All rights reserved.

Dementia handbook for carers

Berkshire West

Legal and money matters

Legal issues **1**

Money matters **5**

Legal issues

A diagnosis of dementia can bring with it some difficult decisions that have legal implications. This section sets out some of the most important decisions for the person you are caring for.

Driving

Dementia can affect a person's ability to drive safely. Even if they feel they are a safe driver, their level of attention and ability to make quick decisions is likely to be reduced. This could put them, their passengers and other people on the road at risk. It is a legal requirement for a driver to tell the DVLA of a diagnosis of dementia. Failure to tell the DVLA may lead to a fine of £1,000.

If someone wants to continue driving they must tell the DVLA. The DVLA will then send them a questionnaire and will ask for their agreement to contact their doctor at the Memory Clinic. The DVLA may then ask the person to have a driving assessment at a special centre. The DVLA's decision will be based on the report of the Memory Clinic and the driving assessment.

If someone wants to check they are still safe to drive they can also book an independent driving assessment, for a fee, at a Regional Driving Assessment Centre.

Sometimes the doctor who gives the diagnosis of dementia will make a judgement that it isn't safe for the person to drive and will tell them to stop immediately. If the doctor has said this then it is illegal for the person to continue driving. They can ask for a second opinion from another doctor but they must not drive until that has been given. The second doctor may still advise that they do not drive.

If someone has a diagnosis of mild cognitive impairment they do not have to tell the DVLA unless they are advised to by their doctor. If

they have any concerns about their driving they should inform the DVLA. If a person with mild cognitive impairment or dementia continues driving they must tell their insurance company, or their insurance may be invalid and they will not be covered if they have an accident.

While some people will readily agree to give up driving, others feel it as a great loss of independence and find it hard to admit they should give up. There is more information on coping with this kind of change in the booklet "Day-to-day living", page 22.

Berkshire Healthcare has detailed information leaflets "Driving and Cognitive Impairment and Stopping Driving" which are available from your Memory Clinic.



For more information contact the DVLA:

call 0300 790 6806 or visit
www.gov.uk/contact-the-dvla

To contact the Regional Driving
Assessment Centre:

call 0845 337 1540 or visit
www.rdac.co.uk/services_driving.php

Making or updating a will

An up-to-date will

A will is an important legal document for everybody. It ensures that after someone dies, their money and possessions are passed on to the people they want them to go to. If the person you care for has no will, they should make one, if they can. While many people have made a will, it may be out of date. You may need to check it is up-to-date and whether they need to change it.

If you have mirror wills with your husband or wife, you may need to seek advice from a solicitor about adjusting your will if one of you is diagnosed with dementia.

Testamentary capacity

If a person needs to make or change a will they must have testamentary capacity. This means they have to be able to make decisions about their will independently. A good first step is to talk to a solicitor about what you need to arrange. Solicitors often charge for this kind of advice so it is advisable to get quotes from two or three solicitors. Most solicitors have wide experience of dealing with wills but you can ask for a registered solicitor for the elderly.

The solicitor will decide if they need to take advice about a person's testamentary capacity. This may involve asking a specialist doctor to fill out a form confirming their capacity. If a person does not have testamentary capacity there is still a process that can be used to help them make or change their will. This is through the Court of Protection. A solicitor will advise you on whether this is appropriate and what you need to do.

Finding a solicitor

If you do not have a solicitor, you can ask the Citizens Advice Bureau, Age UK or Alzheimer's Society for lists of local solicitors. They will also have information about making a will that they can pass on to you. There is more information and a search tool to find solicitors who specialise in will making at The Law Society website.



For more information about making a will:

[www.lawsociety.org.uk/for-the-public/
common-legal-issues/making-a-will](http://www.lawsociety.org.uk/for-the-public/common-legal-issues/making-a-will)

www.lawsociety.org.uk/find-a-solicitor

Lasting Power of Attorney (LPA)

Putting arrangements in place

It is likely that in the later stages of dementia, the person you care for will find it hard to make decisions. They may not be able to manage their money or plan for their future. Decision-making may have to be taken over by you or someone else who the person trusts to carry out their wishes. This is done by granting a Lasting Power of Attorney that can be used if they can no longer make decisions.

Many people find it upsetting to think forward to this situation. As an interim you will be able to fill in forms together at their bank so that you can become a signatory to help them operate their account. However, for you to be able to act for them more widely the law requires paperwork to show that they have handed over decision-making responsibility to someone else.

Lasting Power of Attorney can only be set up while the person giving the power is well enough to understand what they are doing; that is, while they have the mental capacity to make the decision to grant a Lasting Power of Attorney. If a person with dementia has not granted a Lasting Power of Attorney before they lose mental capacity, it may require a lengthy (and often expensive) process to put arrangements in place. See the section "Court of Protection", on the next page.

If the person is willing to set up a Lasting Power of Attorney early and knows they have appointed someone they trust to help with decisions it can help reduce their concerns about the future.

There are two kinds of Lasting Power of Attorney:

A Lasting Power of Attorney for Property and Financial Affairs appoints someone to make decisions about a person's money; for example, paying bills and managing their bank account. It can even be used to sell the person's property, if needed. This Lasting Power of Attorney can be used while the person still has capacity to give instructions to the Attorney and when they are no longer able to do so.

A Lasting Power of Attorney for Health and Welfare appoints someone to make decisions about a person's everyday care and future planning. It gives responsibility for making decisions about a person's treatment if they are taken into hospital, but only if they cannot make those decisions themselves.

You can get forms, or advice about where to get a form, to set up both kinds of Lasting Power of Attorney from

- your Memory Clinic
- support agencies such as Age UK and the Alzheimer's Society
- the government website
www.lastingpowerofattorney.service.gov.uk.

The forms have full instructions on them but if you have concerns about filling them out you can also ask advice from a solicitor. Ask if they have a specialist in Power of Attorney.

Once you have filled out the forms and signed them you need to send them to the Office of the Public Guardian to be registered. Forms for Lasting Power of Attorney are not valid until they have been registered and returned to you. There is a fee to register.

 For more information about Lasting Power of Attorney:

www.alzheimers.org.uk/factsheet/472
www.reading.gov.uk/residents/care-and-support-for-adults/protecting-vulnerable-adults-from-abuse/MentalCapacityAct/mental-capacity-planning-ahead

Apply on-line for Lasting Power of Attorney:
www.lastingpowerofattorney.service.gov.uk

Enduring Power of Attorney (EPA)

Lasting Power of Attorney has replaced Enduring Power of Attorney. Whilst an Enduring Power of Attorney can no longer be prepared by a solicitor, if you already have one, it is still valid and can be registered and used. EPA only covers decisions about finances and property.

Court of Protection

If a person has not granted a Lasting Power of Attorney to someone to make decisions for them, but can no longer make decisions for themselves, the family or carer might need to apply to the Court of Protection. This process is more time consuming and expensive than a Lasting Power of Attorney.

Court of Protection is a specialist court that deals with people who lack the capacity to make specific decisions. Under the Mental Capacity Act, the court can make decisions about personal welfare and property and finances and appoint deputies to make decisions on behalf of the person.

You can get forms or advice about Court of Protection from:

- Memory Clinic
- Support Agencies like Alzheimer's Society or Age UK
- The government website: www.gov.uk/apply-to-the-court-of-protection



For more information:

Carers Direct helpline on 0300 123 1053
www.nhs.uk/CarersDirect/moneyandlegal/legal/Pages/MentalCapacityAct.aspx

Mental Capacity Act 2005 (460)
www.alzheimers.org.uk/factsheet/460

The Code of Practice is available online
www.gov.uk/court-of-protection

Advance Decisions and statements

Individuals differ in their feelings about how much they want to control the medical decisions that might be made for them if they need treatment but cannot make decisions for themselves.

These decisions might cover, for example, whether they would want to have resuscitation if they lose consciousness or whether they would want surgery that has a high level of risk or a long recovery time. Some people's wishes will be influenced strongly by their religious beliefs and they will want medical staff to be made aware of these.

If you are able to discuss these issues with the person you care for, they can make Advance Decisions about treatment, which will then be legally binding on doctors caring for them.

An Advance Decision is a signed, witnessed record of what a person wants. It is only valid if it is counter-signed by a witness who can verify that the person had mental capacity at the time they made it. And it will only be used if the person does not have mental capacity to make their own decisions at the time they are in hospital.

Advance statements are more general than instructions about specific, medical decisions. They deal with a range of aspects of care; for example, the kind of food a person would like to have, the people they would like to be consulted about their care. Unlike Advance Decisions, advance statements are not legally binding but medical and care staff will try to follow them.

For both Advance Decisions and statements it's important that the instructions the person gives are clear. The Memory Clinic can tell you where to get forms to record Advance Decisions and statements. It may help to ask the person's GP for help in writing them.

A person's Advance Decision could change their arrangements for Lasting Power of Attorney for Health and Welfare (described on page 3 of this booklet). Although this is unlikely, you should be aware of the possibility.



For more information about Advance Decisions and statements:

www.alzheimers.org.uk/factsheet/143

For an Advanced Decisions form to complete see:

www.alzheimers.org.uk/advanceddecisionform

Money matters

The costs of caring for someone with dementia can mount up. A lot of practical help and advice is provided directly by your health care team or Social Services. There may be other support that you will need to apply for and, if you are not eligible for funding, to pay for.

Finding out what is available

The kinds of financial support change over time because of changes in local and national government policy. You will need to check details of what is available when you need it.

You can get advice from Social Services or from organisations such as Age UK or Alzheimer's Society. There are voluntary organisations that focus on giving advice about financial support. See page 17 of the "Support" booklet.

Local Council support

Council Tax exemption

Following a diagnosis of dementia the person who is diagnosed may be eligible for a discount or exemption from Council Tax. If they are living with another adult this could reduce the Council Tax on their property or if they live alone could exempt their property from Council Tax. To apply for Council Tax Exemption you must be receiving one of the disability benefits, for example Attendance Allowance.

If you are looking after someone and living in the same home, you may be entitled to some further reductions in Council Tax if you also have a disability. If you did not claim Council Tax exemption when you were first eligible for it, your claim can be backdated.

Contact your local Council Tax office to find out more and for forms to apply for exemption.



For more information about Council Tax: www.alzheimers.org.uk/factsheet/414

Council Tax Office details:

Reading

0118 937 3727

www.reading.gov.uk/residents/CouncilTax

West Berkshire

01635 519 520

www.westberks.gov.uk/index.aspx?articleid=22285

Wokingham

0118 974 6022

www.wokingham.gov.uk/counciltax

Daily living equipment and adaptations at home

You may need to make changes at home so that it is easier and safer for the person you care for to move around. For example you may need to put grab rails in the bathroom or on the stairs. At some point you may need a stair lift.

Everyone has the right to a Community Care Assessment of the equipment and other support they may need at home. You can contact Social Services to arrange this, or your Memory Clinic team may make this arrangement for you. If the person's needs change you can ask Social Services to come back to reassess them.

Daily living equipment, such as walking frames or grab rails should be provided free of charge. Disability adaptations costing up to £1,000

(to buy and install) are currently free. If there is equipment that you need to pay for, Social Services will give you information about approved suppliers.

If a person is registered disabled because of their dementia, they do not have to pay VAT on any disability equipment they buy, or its maintenance. So remember to ask any supplier for a VAT exemption form.

Other personal equipment, such as hearing aids or magnifiers for reading, should be provided free but you will need a GP referral for an appointment to assess a person's hearing or vision.

Support for care

A Community Care Assessment will recommend the kinds of social care that will make it easier for the person you are caring for to stay at home or the kind of care home that would be best, if they can no longer be cared for at home.

You can also ask for a Carers' Assessment which will look at the kind of support you might need to help you care for someone. These assessments are described in more detail in the booklet "Day-to-day living", page 3. After assessment you will be given a care plan. The plan might include, for example, help with housework, personal care, meals, or recommendations for day centres that might suit the person you are caring for.

Some support is provided without charge. Other kinds of care are means tested and will take into account savings or income that you have, including state benefits (which are described below). The Government requires the Council to give you information and advice about support services. They must give this advice even if you aren't entitled to funding and are paying for services yourself.

 You can read more about Berkshire Social Services support for care in the Berkshire Care Directory: www.westberks.gov.uk/CHttpHandler.ashx?id=3602&p=0
Printed copies are available at your Memory Clinic and from local support agencies.

Personal budgets

If you or the person you care for are entitled to funding for care services you will be offered a personal budget (sometimes called a direct payment) to pay for them. You can then choose your own providers for those services. For example, if the plan includes day centre visits twice a week, the person can choose the day centre they want to attend; similarly, you can choose who provides personal care. If you don't want to manage your budget yourself, you can ask the Council to manage it for you.

 For more information about personal budgets:
www.ageuk.org.uk/documents/en-gb/information-guides/ageukig26_personal_budgets_inf.pdf?dtrk=true

State benefits that can support the cost of caring

These are benefits from the Department of Work and Pensions (DWP). These benefits are backdated to the day that you started your application for them. Even if you don't have all the information the application forms ask for, it is worthwhile starting off your application to get the full benefit that you may be entitled to.

The application forms can be quite complicated, so ask for advice from your Memory Clinic, local Age UK or Alzheimer's Society support team or from Citizens Advice Bureau.

 For more information about Carers Allowance and disability benefits the Government website has a wide range of information:
www.gov.uk/browse/benefits/disability

Attendance Allowance and Personal Independence Payment

If the person you care for is over 65 and needs help with everyday activities such as washing, dressing and eating, they are likely to be eligible for Attendance Allowance. Attendance Allowance is paid at two levels (higher or lower) according to how much care the person

needs. If the person is under 65 they may be eligible for Personal Independence Payment.

Attendance Allowance (over 65s) and Personal Independence Payment (under 65s) are not means tested and do not depend on how much a person has paid in National Insurance. The person applying for the allowance may have to have a medical examination.

Carers' Allowance

If the person you care for receives Attendance Allowance or Personal Independence Payment and you are looking after them for 35 hours a week or more, then you may be entitled to Carers' Allowance. Unlike Attendance Allowance and Personal Independence Payment, Carers' Allowance is taxable and means tested. If you receive it as a carer it may affect some of the other allowances the person with dementia can claim. So it is worthwhile seeking advice before claiming it.

Additional benefits

If you are of pensionable age and either do not have a pension or cannot live on your pension you may be entitled to Pension Credit, which provides additional income to support you. If you are below pensionable age you may be entitled to Income Support. If you are married or have a partner you must apply for these benefits as a couple.

If you are of pensionable age you should be entitled to Winter Fuel Allowance. If the temperature in your area falls below freezing for seven consecutive days, and you are on Pension Credit or Income Support, you will receive additional Cold Weather Payments.

As with Attendance and Carers' Allowances, applying for these benefits can be complex and it may be wise to ask for help from your Memory Clinic, local Age UK or Alzheimer's Society support team or Citizens Advice Bureau.



For more information about benefits:

Pension service 0800 731 7898

Attendance Allowance 0845 712 3456



Berkshire Healthcare NHS
Foundation Trust
Fitzwilliam House
Skimped Hill Lane
Bracknell
RG12 1BQ

Telephone: 0118 960 5027
www.berkshirehealthcare.nhs.uk

© Berkshire Healthcare NHS
Foundation Trust 2014.
All rights reserved.

Contacts

Use this list for people who are important for the care of the person with dementia. It may be helpful to add next of kin, close relatives, and neighbours who help out. We have listed some key contacts. Please add others that are relevant to you, such as care agencies, transport providers.

Name/service	Phone or contact details
GP	
Westcall, Out of hours GP	111
Memory clinic, dementia advice and care	
Local hospital	
Pharmacy	
Late night pharmacy	
Social worker	
Dementia care advisor	
Solicitor	

Medication record

1 List of medicines

Add here a current **list of medicines** and, **include the times of day they are taken**. You can ask your GP to provide a print out of current prescriptions.

Don't forget to add a list of current medication here!

Medical staff need this list before discussing any treatment.

2 Allergies/reactions to medicines

List allergies to and side effects of medicines, e.g., stomach problems or drowsiness.

3 Other medicine taken

List any other medicines or herbal remedies which are not prescribed by your doctor.

Medicines with known side effects

All medicines have some side effects. This should not put someone off taking medicine that is essential. If you notice side effects, discuss them with your doctor.

Medicine type	Medicine name	Common potential side effects
pain killers: opiates	Codeine, Cocodamol, Codydramol, Tramadol	drowsiness, constipation, worsening confusion
pain killers: NSAIDs	Diclofenac, Brufen, Naproxen	heartburn (gastric irritation), gastric bleeding (black stools), kidney problems
water tablets/ diuretics	Bendroflumethiazide, Furosemide	needing to urinate at night, reduced sodium levels resulting in confusion
antidepressants	Citalopram, Sertraline, Fluoxetine	reduced sodium levels resulting in confusion, loose stools
antidepressants	Amitriptyline, Dosulepin	drowsiness, worsening confusion, urinary retention, constipation
sleeping tablets	Lorazepam, Temazepam, Diazepam, Zopiclone, Zolpidem	drowsiness, increased risk of falls
blood thinners	Warfarin, Aspirin, Clopidogrel	increased risk of bleeding, bruises in case of falls

Pain assessment

You know the person you care for well. If you think they are in pain it may be useful to complete this checklist in order to discuss their symptoms and treatment with medical staff.

1 How often do they feel pain?

- constantly
- it comes and goes
- it is very sudden and short
- it is only during specific activities

2 Do they use words to describe their pain?

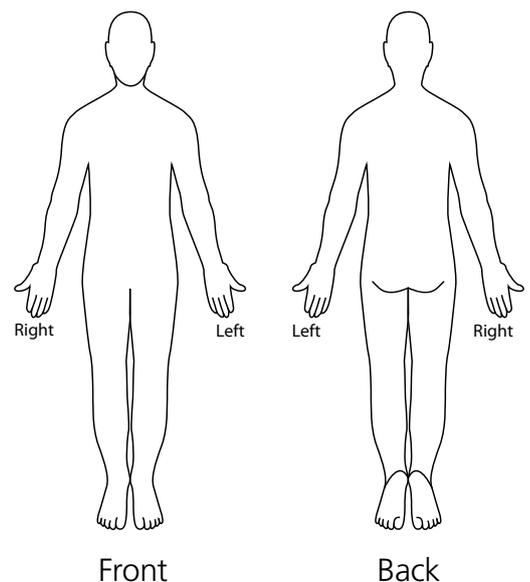
- No
- Yes
 - burning
 - shooting
 - stabbing
 - aching
 - Other: _____

3 Do they cry out with pain?



4 Where does it hurt them?

Please show on this drawing.



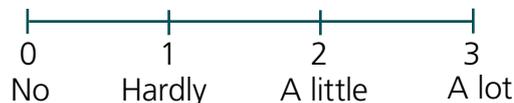
5 Does their face ever show pain?



How does their face show pain?

- looking tense
- frightened
- by frowning
- Other:

6 Has their body language changed recently?



How has their body language changed?

- fidgeting
- rocking
- guarding part of the body
- hunching
- Other:

7 Has their behaviour changed recently?



How has their behaviour changed?

- increased confusion
- problems with eating or sleeping
- irritable or aggressive behaviour
- wanting to be left alone
- Other:

8 Are there specific activities that they find painful and resist doing?

- No Yes
- washing
- getting out of bed
- climbing stairs
- Other:

9 Have you noticed any possible causes of pain?

- No Yes
- cuts
- bruises
- arthritis
- recent falls
- Other:

10 Are there things that seem to help to soothe their pain?

- No Yes
- having a hot drink
- blankets
- hot water bottles
- cold compress
- having an alcoholic drink
- smoking
- Other:

Services and support checklist

This list shows key support services and information. Not all will be appropriate for you. Your health professionals will talk through the list and sign to show what has been discussed.

Item and handbook reference	Discussed	Date	Signed
Carer support			
Memory Clinic carers course: Day-to-day living, page 3	[Yes] [No] [N/A]		
Organisations: Support, page 6 (Age UK, Berkshire Carers Service, Carers UK, Crossroads)	[Yes] [No] [N/A]		
Dementia Café: Day-to-day living, page 21	[Yes] [No] [N/A]		
Carers' Assessment (Social Services): Day-to-day living, page 3	[Yes] [No] [N/A]		
Patient support			
Community Care Assessment (Social Services): Day-to-day living, page 3	[Yes] [No] [N/A]		
Cognitive Stimulation Therapy: Medication and treatment, page 2	[Yes] [No] [N/A]		
Talking Therapies: Medication and treatment, page 2	[Yes] [No] [N/A]		
Community activities: Day-to-day living, page 21 and Support, page 12	[Yes] [No] [N/A]		
Support for decision making			
Driving: Day-to-day living, page 22 Legal and money matters, page 1	[Yes] [No] [N/A]		
Respite care: Day-to-day living, page 4	[Yes] [No] [N/A]		
Nursing care: Day-to-day living, page 7	[Yes] [No] [N/A]		
Advance care planning: Day-to-day living, page 29	[Yes] [No] [N/A]		
Other			

Consultation checklist

Here is a list of things that you should expect to be covered during Memory Clinic diagnosis.

Discussed or reviewed			
Investigations: Blood and/or brain imaging investigations reviewed	[Yes]	[No]	[N/A]
Medication review	[Yes]	[No]	[N/A]
Psychological support	[Yes]	[No]	[N/A]
Cognitive function	[Yes]	[No]	[N/A]
Support for carer	[Yes]	[No]	[N/A]
Taking part in research	[Yes]	[No]	[N/A]
Memory Clinic and Social Services contact details	[Yes]	[No]	[N/A]
Reading			
• Hazelwood Memory Service: 0118 960 5959			
• Social Services: 0118 937 3747			
Newbury			
• Beechcroft Memory Clinic: 01635 292 070			
• Social Services: 01635 503 050			
Wokingham			
• Barkham Memory Clinic: 0118 949 5101			
• Social Services: 0118 974 6772			
Follow up consultation (how often and with whom)	[Yes]	[No]	[N/A]
Copy of letter to patient/carers	[Yes]	[No]	[N/A]
Remind GP to add to the General Practice Dementia QOF Register	[Yes]	[No]	[N/A]