A–Z of symptoms and behaviours
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.

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.

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”.

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
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

Balance See Falls
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.

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.

For more information:
See Aphasia/dysphasia, Decision Making
BUPA’s Talking Toolkit
www.bupa.co.uk/individuals/health-information/dementia
Communicating
www.alzheimers.org.uk/factsheet/500

Bladder or Bowel problems See Constipation, Incontinence

Choking See Eating and drinking
**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.

*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.

*For more information:* See, “Everyday activities” on page 18 in the “Day-to-day living” booklet.

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**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.

*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.

*For more information:* See Delirium, Memory

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**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.

*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.

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.

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.

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?”.

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.

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
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

Denial See Lack of insight

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.

**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** 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.

**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.
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.

**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.

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
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.

For more information:
See Misperceptions
Sight, perception and hallucinations in dementia
www.alzheimers.org.uk/factsheet/527

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See Misperceptions
Sight, perception and hallucinations in dementia
www.alzheimers.org.uk/factsheet/527
**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 to go to 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

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**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
**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.

**Lack of insight 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.

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**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 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 Fronto-temporal 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
**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.

**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.

For more information:
See Pain, Sleep disturbance, Wandering
Assistive technology
www.dlf.org.uk/factsheets/telecare

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**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.

**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.

For more information:
See, “Pain” on page 25 in the “Day-to-day living” booklet
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.

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 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

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.

**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.

**For more information:**
Unusual behaviour
www.alzheimers.org.uk/factsheet/525

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**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.

**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.

**For more information:**
See Anxiety, Wandering
**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.

**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.

For more information:

See Lack of inhibition
See Sex and dementia
www.alzheimers.org.uk/factsheet/514

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**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.

**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.

For more information:

See Night walking, Pain
**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.

**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.

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**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.

**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.

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For more information:
See Anxiety, Depression, Personality change

See Falls, Hallucinations, Misperceptions

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