

Behavioural changes

Behavioural changes in someone with dementia can leave you feeling irritated, upset, angry, tired and at the end of your tether.

Relationships change

You are likely to find the relationship between you and the person you care for changes. This is not because either of you loves or cares for the other less than you did before. The dementia simply makes it harder for the person to remember things and to understand what is going on.

You may find they don't remember all the things you do for them, or that you came to see them yesterday. They may not recognise that they need help and question why you are there. Or they may demand to know why you aren't doing more to help them.

You may feel you've lost the person you once knew. You may feel sadness that you've lost the life you had together, and the life you planned together. You may feel grief that you've lost the person who was your lover, friend and companion.

Any of these reactions can be upsetting to deal with, as well as frustrating and angry-making. Remember, it's not their fault; it's the fault of the dementia. Try not to take it personally.

Even when you come to some sort of acceptance, you may well find their mood and behaviour changes again as the dementia progresses, and you have a fresh set of feelings to deal with. This is entirely natural, and other carers experience exactly the same feelings.

Communication

Being able to communicate with other people is vital. It helps us express our needs, our feelings, our sense of belonging, our sense of our own identity. Over time, someone with dementia will find it harder to communicate in the way they used to.

They may forget words, peoples' names, familiar places. They find it harder to process information. Plus simply struggling to understand what is going on around them makes it harder for them to express themselves.

This can all give rise to a lot of misunderstandings.





Practical tips for improving communication with someone with dementia

Here are some simple techniques you can use to help the person express themselves and understand you, and for you to understand them. Remember that not all communication is verbal. Facial expressions, gestures and touch can all 'say' a lot.

Above all, no matter how irritated and exasperated you become with the lack of understanding or repeated questions, remember the person is not deliberately trying to be annoying. Take a deep breath or, if necessary, leave the room for a while. Getting cross with the person will only upset them, or make them more frustrated.

Speak clearly and make sure the person can see you clearly.

Make sure you are on the same level as the person you are talking to – sit down next to them or kneel down and create eye contact - it can make all the difference.

If you're asking a question, keep it simple rather than giving lots of options.

Consider writing down questions, the person may be able to understand the written words more easily. Also consider using pictures as visual prompts e.g. a photograph of a family member who you are chatting about.

The person with dementia may be able to communicate with you by writing.

Allow them time to answer. Processing information will take them longer, and they'll grow agitated if they feel they're under pressure. Just sit quietly, or use prompts of names and places that you know are familiar to them.

Listen carefully to them and don't give any appearance of trying to rush them or impatience. This will make them more agitated.

If they're struggling to get the right words, ask some simple questions to help them to express it in a different way. Don't be tempted to finish off someone's sentence. That can be very annoying!

Try and make them laugh. Humour is a great way to relax someone, and they then might easily remember what it is they were trying to say without struggling.

Don't look agitated, impatient or in a hurry while you're talking to them. This will make them feel agitated and as though you don't have time for them, and they'll find listening and talking even more difficult.

Don't contradict something they have said, even if you know it to be untrue. Try and relate it to something that is real. For example, if they say they have to go to work, you could reply by saying "yes, you used to catch the bus to work, didn't you?"

Always try to include them in conversations when other people are with you, even if they can't follow what is being said. It gives them reassurance and stops them feeling so isolated.

Never forget the importance of a hug, a smile or holding hands.

Is hearing a problem for the person with dementia? They may need to visit their GP for a referral to an audiologist. It could just be impacted ear wax.

If they have hearing aids remember to check that they are clean and working correctly, including the batteries. Poor vision will affect communication.

Does the person with dementia need or wear glasses? If they wear glasses makes sure that they are clean.

Recognition

As someone's dementia progresses, they will gradually forget who people are, and may confuse you with someone else. This is common, and for many people that loss of recognition can be the most painful aspect of dementia. Try to remember that it's not the person's fault. Although they might not remember who you are, they may well respond to you with affection. On other occasions, they may respond with aggression. This is partly because the person may be aware of what is happening to them, but is unable to express their feelings, or they are confused, anxious and frightened, because everything around them is unfamiliar.

Remember when you were a child and were lost, frightened and didn't know what to do, how disturbing this was. This is how it feels to have dementia. It's not unusual for people to talk about people and places from a long time ago, as if they are with those people and in those places now. Talk to the person about their experiences and try to show you understand. Don't try to persistently tell them that they are wrong, it will only agitate them - remember, to the person with dementia, it is very real.

Coping with behavioural changes

Dementia will change the behaviour of the person you have known.



Understand the reasons

Behavioural changes are particularly common amongst people who find it hard to express what they're feeling verbally. But they can leave you feeling irritated, upset, angry, tired and at the end of your tether. Trying to understand why the person is behaving as they are can help you work out how to deal with the situation.

Remember, the person is not being deliberately difficult. To them their behaviour makes perfect sense. Remember, also, most types of unusual behaviour are because the person is trying to tell you something, or express something. Find out what that something is, and you're half-way there to solving the problem.

Typical behaviour patterns

Below are some tips for coping with typical behaviour patterns associated with dementia:

Repeated questions

The person may be feeling anxious about their ability to cope, and the repeated question may not be the real issue. Encourage them to find the answer themselves and reassure them that everything is OK. For example, if they keep asking the time, point out the clock and ask them to read it.

They may be anxious about a past activity such as going to work or picking children up from school. If, for example, the problem is one of picking up the children, you could try talking to them about the children- this is about recognising their anxiety and validating them as a person. You may find it useful to suggest to the person that they look at something different, for example their life story book, or an object that is familiar and important to them to distract them from their fixation. Sometimes a change of scenery helps – so take people for a walk or visit a friend.

Repeated actions or movements

The person may just be bored. Consider what kind of life they have led...was it a busy life? If this is the case then being inactive will lead to boredom and the individual will be looking for something to do. Encourage them to do



something they enjoy, for example, go for a walk, play a game of cards, arrange for a friend to visit. It could be a stage of their dementia, but if in doubt contact their GP. It could be the sign of an infection or a side-effect of their medication or they may be experiencing pain. Sometimes, physical contact and interaction can calm people – try holding their hand and singing to them, or talking to people in a soothing voice.



If the behaviour is problematic then you need to contact their GP. You may be referred to behaviour support specialists who can help develop individual programmes that can combat some of these symptoms.

Lack of inhibition, such as undressing in public

This could be a sign that they want to go to the toilet or that they are genuinely hot and uncomfortable. Or it could be that the person has reached a stage with their dementia where they have lost their inhibitions. Don't shout or act harshly. Take them somewhere private and tell them when their behaviour is inappropriate. They may just be agitated and anxious and have forgotten normal social codes of behaviour. Talk to them calmly, reassure and then distract with another activity.

If this is a recurring problem around one or two people, try and avoid leaving people on their own with someone. Remember, if people are aware of their actions and there is mutual consent there is no reason why people with dementia cannot enjoy appropriate sexual relations. If the person's lack of inhibition or sexual behaviour becomes problematic you should contact their GP. You may be referred to behaviour support specialists who can help develop individual programmes that can combat some of these symptoms.

If your reaction is that this shouldn't be allowed, examine why you feel like this. Sometimes people just want physical contact and comfort, and remember people with dementia are still individuals.

Restlessness and fidgeting

This could be a sign they are hungry, thirsty, in discomfort or want to go to the toilet. Try and find what's upsetting them. If none of these are the reason, they may just be bored - distract them with something physical, such as a walk or other meaningful activity.

Following you around

Having dementia can make a person very insecure and anxious. Even though you've only just talked with them, they may well have forgotten and are checking you're still in the house. Talk quietly and reassuringly and try not to lose your temper – if you do, try not feel guilty as you are only human. Give them something meaningful to do to occupy them or put the radio or some music on if that is what they enjoy.



Hallucinations

Hallucinations are when people see or hear things that are not there. They are not the same as illusions or visual misinterpretations, which all have a logical explanation - for example, 'seeing' a face on the wall, which is in fact part of the pattern of the wallpaper, your own reflection in a mirror, or leaves on the floor which are part of the carpet pattern.

Not everyone with dementia experiences hallucinations. They are most common in people with Dementia with Lewy Bodies – you can visit the Lewy Body Society website for more

information (www.lewybody.org). Not everyone who has these problems has dementia. Not all hallucinations are bad experiences.

Before concluding that someone is experiencing hallucinations, consider whether there could be other causes:

- the side-effects of medication or an infection
- poor lighting, eye-sight or hearing
- using the wrong words to describe something
- talking to themselves because they have lived on their own

Possible triggers for hallucinations

By observing people's behaviour, find out if there are any triggers that are causing problems - common ones are:

Certain times of day, maybe when they are tired.

Mirrors and reflections in glass. Try removing these or covering them up.

Television, particularly violent programmes or fighting which can be disturbing to some people with dementia. You can limit access to certain types of programme - ask someone to help you to do this if you are not sure yourself, or even go to the radical stage of switching it off, and doing something else.

Try playing DVDs or taping programmes that are suitable to watch. Although some people with dementia do not have long attention spans, other people are fine and can follow a film or a favourite comedy programme - perhaps one they used to watch years ago.



Caring for someone experiencing hallucinations

Don't disagree with the person about what is happening to them. To them what they have seen or heard is real.

Don't argue or make the person feel foolish.

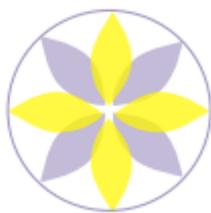
Offer them comfort and reassurance, such as a hug or stroke their hand, then try to distract them.

Try to make sure they are always occupied.

Tell them that, although you can't see or hear what they're experiencing, you want to know more about it. Then try to make it less alarming and frightening, or try to offer some rational explanations.

Keeping good light levels and background noise to a minimum will help reduce the chances of further confusion.

Keep an eye on the regularity of the hallucinations - it could be the sign that there is an underlying cause, such as pain or medication. You should then contact their GP.



Problems sleeping

People with dementia often experience changes in their sleeping patterns. They may sleep more lightly, need less sleep, wake up at unusual times or not recognise normal bedtimes and getting-up times. There is the additional problem of them walking about in the night, and potentially getting into difficulties.

All of these things can make life more exhausting for you as a carer, and interrupt your sleep. It's important that you try to find ways to help them sleep better, not just for their well-being but also to ensure you get sufficient rest.

Getting a good night's sleep

The following are some practical tips to help both the person with dementia and you to get a good night's sleep:

Make sure the person with dementia is genuinely tired by the evening so they will naturally sleep. Avoid too many daytime naps (often these are out of boredom rather than a genuine need for sleep). Exercise also helps make someone tired.

Mid to late afternoon a person with dementia may show signs of irritability and restlessness. This is thought to be associated with light changes and tiredness. This is commonly referred to as Sundowning. A person with dementia may benefit from a short nap in the afternoon.

Make sure they have been to the toilet just before getting into bed.

Keep to their regular bedtime routine or start one if they don't have one. Perhaps a milky drink, warm bath, putting on the radio for quiet music.

Put away all distracting 'daytime' things - clothes, newspapers, books etc.

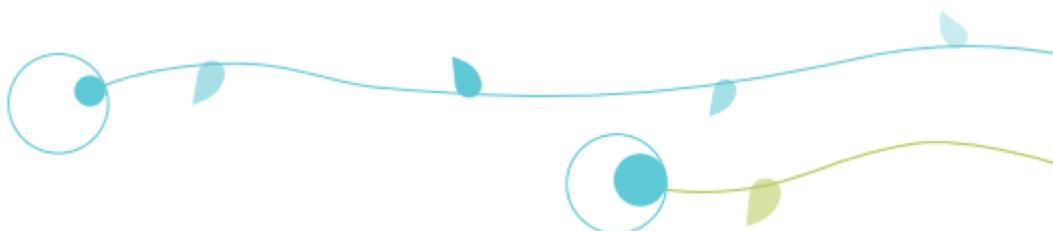
Make sure the room is dark but perhaps with a night-light for reassurance or to help them find the way to the toilet.

An alarm pressure pad under the mattress can alert you if the person gets up. If the person moves around a lot whilst in bed, try a pressure pad on the floor next to the bed or an infra-red movement detector to alert you if the person gets up. This can be connected to a buzzer in your pocket or under your pillow.

If you share a room with the person with dementia, do they still recognise you as someone they share a room with? If so, you may need to consider changing where you sleep. This can benefit both of you.

There is more information on dementia and sleeping on the National Sleep Foundation website (www.sleepfoundation.org).

To find products that may help, you could have a look at the Unforgettable website (www.unforgettable.org).



Support organisations

For more information or advice, please call Dementia Care on 0191 217 1323 and ask to speak to one of our Dementia Guides. They offer free face-to-face support for people with dementia and their families in Newcastle upon Tyne, Hexham and the surrounding areas.

A variety of support groups will exist in your local area. To find out who they are and how to contact them, it may also be useful to contact some of the national organisations listed here:

Age UK
www.ageuk.org.uk
or call 0800 169 2081

Alzheimer's Society
www.alzheimers.org.uk
or call 0845 300 0336

The Lewy Body Society
www.lewybody.org
or call 0131 473 2385

Carers UK
www.carersuk.org
or call 0808 808 7777

The Princess Royal Trust
www.carers.org
or call 0844 800 4361

Concerns regarding financial or other abuse of a vulnerable person

If you have any concerns regarding financial or other abuse of a vulnerable person, you should contact the Office of the Public Guardian:

PO Box 16185
Birmingham
B2 2WH
Tel: 0300 456 0300 or
Email: customerservices@publicguardian.gsi.gov.uk

Opening hours:
Monday, Tuesday, Thursday and Friday - 9 am to 5 pm
Wednesday - 10 am to 5 pm

