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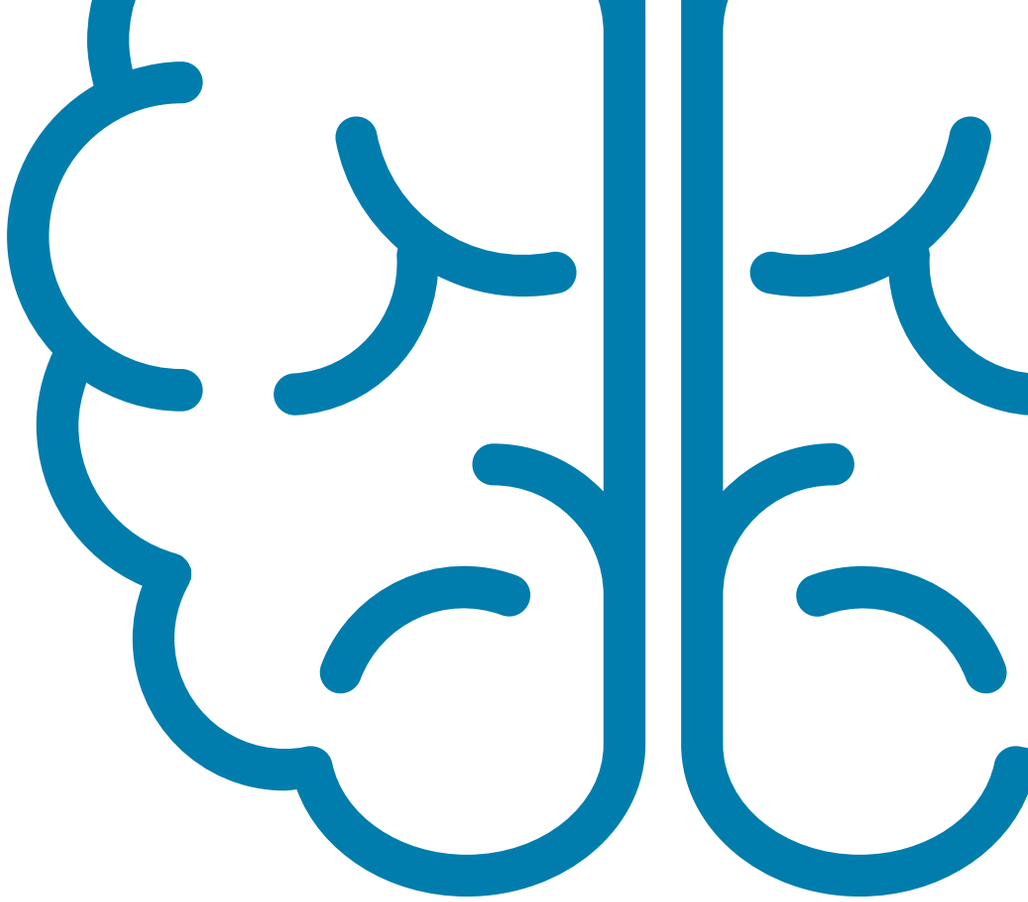

A straightforward guide to dementia

Understanding and managing symptoms and behaviours

Dementia Oxfordshire

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Introduction

The Dementia Oxfordshire Team

This guide has been developed for people living with dementia and for their carers and families. It has been created with the help of our Experts by Experience groups - people with lived experience of dementia. Some are living with dementia and others care for someone who has a diagnosis of dementia. Their words are included throughout.

The guide covers many of the topics that regularly come up at our free Information Sessions, and builds on the work of other organisations working with people who are living with dementia.

Each section focuses on a common symptom or behaviour. Not everyone with dementia will display all these symptoms, but most carers will recognise some of them. Some of these behaviours can be worrying and sometimes stressful. They can make caring for someone with dementia very challenging, and carers often feel at a loss about what to do.

In the first part of each section, we explore what may be causing the symptom. In the second part, we suggest ways to support the person with dementia and manage the behaviour.

Living with dementia can be lonely and isolating. We want this guide to help people with dementia and their families and carers to understand they are not alone.

Memory of recent events

At its most basic, our memory tells us whether we are in a familiar, safe place or whether we need to be afraid or run away.

Memory loss is what most people think about when they think about dementia. However, the impact on memory can vary depending on the type of dementia. Some may even forget or deny that they have a dementia diagnosis or might not recognise they have memory problems.

About the symptom

A person with dementia may:

- Forget the topic of conversation
- Repeat themselves
- Forget someone's name
- Be unable to remember how they arrived somewhere
- Leave a task incomplete because they have forgotten what they were doing

Understanding the symptom

In its most basic sense, memory can be divided into two types: a 'short-term' store and a 'long-term' store. The short term store is memory that is related to events that are presently occurring, such as you reading this sentence or talking on the phone. The long term store describes memory of past events and experiences, including the memory of how to do things such as riding a bicycle. It is also responsible for language-based memory such as knowing that the sky is blue or knowing when your birthday is.

> "I leave the radio or television on upstairs if I've left my phone charging up there. I go upstairs to turn them off, and then I remember my phone. It's a system. I get cross if my husband turns the television or radio off, as then I will probably forget about my phone."
>
> **Marianne - Living with dementia expert**

Managing the memory of recent events

> “Having a calendar of upcoming events is helpful – it reassures me that the event is scheduled.”
>
> **Glenn - Living with dementia expert**

Loss of memory is typically one of the earliest signs of dementia and affects almost every aspect of daily life. It is important to know what to expect and how to deal with this challenging symptom. Try a few of these practical tips for supporting someone living with memory problems:

Gently prompt as needed

The person with dementia may need prompts in order to recall names of people in conversation or to complete a task. This can be done by saying the person’s name regularly during conversation. Kindly reminding the person of the next step of their task, handing them the item(s) needed to complete the next action, or reintroducing yourself during the conversation are some of the ways that this can be done.

Consider the time of day

The person with dementia may find it more difficult to remember things when they are tired. Avoid tasks which require a lot of memory ability such as visiting friends during these times. The person living with dementia may need you to provide prompts more often if such activities cannot be avoided.

During a conversation

Make conversation easier by being sure to get their full attention. It’s a good idea to face the person and make eye contact. Speak in a soft, calm voice, and try to avoid complicated instructions and long words.

Break up information

If you need to give someone with dementia instructions, break them down into step-by-step tasks that can be completed individually. Some people with dementia find written instructions easier.

Be more direct

Try asking ‘Would you like a cup of tea?’ for instance rather than ‘What would you like to drink?’. If verbal communication is difficult, try using pictures to spark interest.

> “If I ask Janice where we walked yesterday, she’ll say she doesn’t remember. But if I ask if she remembers any features of the walk, she might say ‘somewhere with a lot of water’, so I will ask her, what has a lot of water? She’ll say “A lake?’, and I will prompt her to think about something else that has a lot of water. “A reservoir?” Yes!”
>
> **Phil – Informal carer expert**

Repetitive questioning

Repetitive questioning (repeating the same questions) can be tiresome and frustrating to families. Even the most well-intentioned carer may feel overwhelmed at times. People with dementia may become upset or angry when told that they are repeating themselves.

> “I often ask the same questions - my wife just repeats the answer and she also hears me tell the same stories. It does not upset her, but it might be best to talk about it.”
>
> **Glenn - Living with dementia expert**

About the symptom

A person with dementia may:

- Repeat words or phrases
- Repeat questions about the time of day, appointments or past events
- Tell the same story several times in a single conversation

Understanding the symptom

Repeating a question is often misunderstood as a need for information. In fact, recent medical studies have found that the use of repeated questions may often indicate that the person with dementia needs to be reassured about something, or that they simply want to be involved in a conversation.

Imagine how frightening and confusing the world would seem to you if you had difficulty understanding how one event in the day flows into the next. You may worry about the future if you could not process events in a logical sequence.

Repetitive questioning may indicate that the person with dementia is anxious, bored or feeling insecure. A person who asks what day or time it is, over and over, may need help understanding the order of activities, and to be reassured that you will not, for example, forget their next doctor’s appointment.

> “The most common question for us is - what are my plans today? That gets repeated frequently in the evening.”
>
> **Kay - Informal carer expert**

Managing repetitive questioning

This difficult symptom can cause the most dedicated carers to lose patience and feel stressed. Before you reach crisis point, try a few of the following tips for managing repetitive questioning:

Identify the cause

If they are asking what time it is, could the time reflect something important they used to do, for example pick their children up from school or go to work? Or are they worried about an upcoming appointment? If you can identify the cause, it can be easier to reassure the person, so for instance, you could say 'the appointment isn't until next week, don't worry I will get you there on time'.

Repeat the answer

Answer the question as if you've heard it for the first time. It's likely the person genuinely can't remember asking and it is evidently something that is of importance to them.

Change the subject or activity

You can try changing the subject to a new topic or offer to do a different activity. Changing the subject/activity might help take their mind off their question.

Reminder of the day & daily schedule

You can try listing the date and any planned activities or appointments on a whiteboard or notepad in a place you know will be visible throughout the day. As well as displaying the information, chat through with them each day what is happening.

Reduce confusion

You can track the repetition for a few days. Does it increase at certain times of the day or with the number of people around? If so, try to occupy them with new activities during those times of day, or keep the number of people to a minimum.

Schedule a break

You can reduce your own stress level by having a visitor or watching a regular television show. Don't forget – you too may need support once in a while.

> "I was getting stressed over repeating the same answer, but now I just tell Glenn. I've trained my mind to just tell Glenn in a way which doesn't remind him of his diagnosis."
>
> **Christine - Informal carer expert**

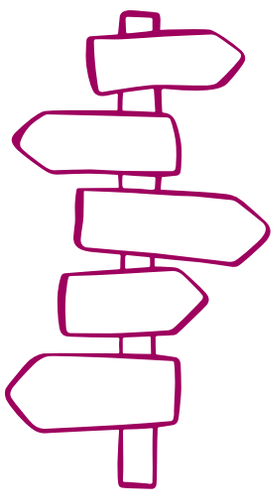
Loss of initiative

Loss of initiative can be challenging for families. You may find the person with dementia begins to lose interest in doing things they used to enjoy, and it can be hard to motivate them to do anything. This can be very isolating, both for the person who is living with dementia, and for their carers and families.

About the symptom

A person with dementia may:

- Spend a great deal of time sitting in a chair or in bed
- Show less interest in daily tasks or activities (for example, cooking, bathing, watching TV)
- Be uninterested in the lives of others or current events



> “Having a routine really helps with initiative. Keeping notes around also helps remind me what I need to do.”
>
> **Kay – Informal carer expert**

Understanding the symptom

Although loss of initiative is sometimes present before the diagnosis of dementia, it generally occurs in early dementia and becomes worse as the condition progresses.

Loss of initiative can be understood in many ways. It can be the person telling you that they are unsure of what to do next or needing more support in starting an activity in their own way. The person you care for might become less interested in daily tasks and activities, even ones that they are still physically able to perform such as reading the newspaper, visiting a neighbour, or going for a walk. They may show little interest in current events and in the lives of those around them.

> “Janice always says that she does not want to do something because “I’m frightened of getting it wrong”. But if I gently aim her in the right direction she can invariably do it. She feels more confident if I keep an eye on her.”
>
> **Phil - Informal carer expert**

As the condition progresses, they might even appear reluctant to complete personal care tasks such as bathing or dressing.

It's helpful to understand that getting out of bed and starting the day requires motivation. While the person you care for may appear 'lazy' or 'apathetic', remember that they have damage to specific parts of the brain which has resulted in this change. That is why they cannot simply be 'talked into' showing interest. However, they can be prompted to do specific tasks.

> "She struggles to tell me what she wants to do, so I help her to talk about the things she enjoys and we piece it together between us."
>
> **Informal carer expert**

Managing the loss of initiative

It can be very difficult to watch the person you care for lose interest in things that they once enjoyed. You might feel as though there is nothing you can do, but the following tips can help:

Create a routine

Giving the person you care for something to do each day can help encourage them in various activities.

Lack of initiative can also be a symptom of depression

If it persists for an extended period of time, or is accompanied by a low mood, weight loss or problems with sleeping, it is important to speak with your GP.

Schedule activities that they enjoy

Most people enjoy some activities over others. Consider the type of work or activity that they used to do. For example, if they used to play football, they may enjoy going to watch a local game.

Bring stimulation to them

The smell of coffee or breakfast helps some people to get out of bed in the morning. You might try this, or similarly, you could play music or bring the newspaper to them. Simply going for a drive can be stimulating.

Bring social life to them

Invite friends or relatives over. This might encourage them to go visiting next time.

Be mindful of the time of day

If there is a specific activity or topic of conversation you want to share with the person, try and pick the time of day where they are at their best. This way they may be able to contribute more.

Misplacing or losing objects

Misplacing or losing objects can cause feelings of anxiety and frustration for both the person with dementia and those who care for them. It can be especially difficult when the person with dementia believes that someone has stolen or hidden the object.

About the symptom

A person with dementia may:

- Not recall using an item or forget where they placed it
- Place items in odd places or hide them from others
- Accuse others of stealing or hiding their items
- Search for items they believe are lost or missing, which do not even exist

Understanding the symptom

The process for remembering what is lost while looking for it is somewhat complex – both for people living with and without dementia. You must hold the image of what you're trying to find in your mind and remember why you're looking for it. Then, remember far enough into the past to remember the last time you used it or where you put it.

When someone has dementia, the parts of the brain that allow for such a complicated memory task can be damaged.

Think about memory like putting something in a box, you keep it there and you take it out when needed. When someone misplaces an object, their problem is not being able to get the memory out of the box. For the person with dementia, the memory exists in their mind initially, but is then lost; it is no longer 'in the box'.

> "He'll say "I don't know where the fridge is" when he is looking at the fridge!"
>
> **Informal carer expert**

Managing misplacing or losing objects

> It's helpful to have the work surfaces clear to start off, so your brain is clear, as clear as possible. If there are lots of things that don't live on the surfaces, then I can't come to it fresh. It makes my brain have to work a lot harder.” **Marianne - Living with dementia expert**

While this symptom can be demanding and can create a sense of helplessness for even the most devoted carer, there are a number of tips which may help:

Use visual cues

You can help the person with dementia to get through their day with less frustration. Try placing labels on drawers and cupboards and/or signage on doors. The use of bold colours (such as blue) are a good way to make these stand out.

Reduce clutter

Something as simple as clearing shelves, tables and countertops can eliminate hiding spots and decrease the number of items that can be misplaced.

Engage in other activities

When the person you care for is compulsively searching for a non-existent item, you may find it helpful to distract the person with chores, hobbies or recreational activities. This can help to reduce feelings of frustration and anxiety.

Have duplicates of essential items

Keep extra toothbrushes, keys and pens in a safe place. This will help to minimise frustration when the original item is misplaced and may help to reduce accusations from the person you care for that the item was stolen or hidden.

Provide guidance through the memory process

Try prompting the person to describe the location or situation in which they last used the item.

Keep valuable items in a secure place

Locking such items in drawers or cabinets can help to prevent them from being moved or lost.

Help to look

Two people searching together are likely to find the misplaced item sooner, allowing you both to move on to a new activity.

> I put things in a certain place to remind myself, you know, I mustn't move that until I've done that, you know, I do a lot of that.” **Informal carer expert**

Anxiety and worry

Anxiety and worry are common in the face of any life-altering or progressive illness. Different people manage their anxiety and worries in different ways. We encourage people to share their concerns with others as this can reduce stress and the sense of isolation.

About the symptom

A person with dementia may:

- Feel anxious about not being able to do what they used to be able to do
- Be afraid of missing appointments or forgetting important dates
- Worry about being separated from their carer
- Have concerns about their future (for example, progression of the condition, new situations)

> “I tie my reassurance to an event Colin is likely to remember. Example: I go out for the day once a month. He is reminded that I will return in time for us to watch Pointless and the 6 o'clock news together. He remembers - and is reassured - by the sequence. For us, a good hug, proper contact, helps. The hug is a reminder of the connection that exists between us.”
>
> **Informal carer expert**

Understanding the symptom

Dementia upsets the delicate balance of brain chemicals that allows us to cope. This is not always bad; some people with dementia find that they worry less. Treating symptoms of anxiety and worry in dementia must be done cautiously because sometimes medication used to relieve anxiety can make other symptoms of dementia worse. On occasions, the medications used to treat dementia can improve anxiety.

> My wife is a worrier – she makes a ‘funny little noise’ when she’s worried so I know when she’s feeling anxious.”
>
> **Stuart - Informal carer expert**

Managing anxiety and worry

Experiencing anxiety and worry can be stressful and difficult to accept for the carer. Although you cannot make the symptom disappear, the following tips may help:

Consider possible causes for anxiety

If the person you care for is anxious about forgetting appointments or tasks, try memory aids such as whiteboards to list weekly activities. If they are often worried about a task which has already been completed, include a place on the whiteboard where they can check off items when complete.

Consider the environment

Think carefully about your home environment. Are there some common or recurring factors which repeatedly result in anxiety? Try to reduce or eliminate noise level, visual clutter or anything that seems to trigger anxious feelings.

Try calming techniques

Identify what soothes the person you care for e.g. music, a drive, a warm bath or a visit with a pet. Try and integrate these things into their daily routine to help build a comfortable and relaxing environment. Similarly, the person you care for may benefit from relaxation therapies, such as breathing exercises or massage.

Encourage exercise

A regular exercise routine or getting out in nature often helps to relieve stressful feelings. If the person you care for can do so, encourage physical activity such as a short walk or dancing.

Carers need self-care

Signs of anxiety such as pacing or repetitive questioning can be upsetting to the carer.

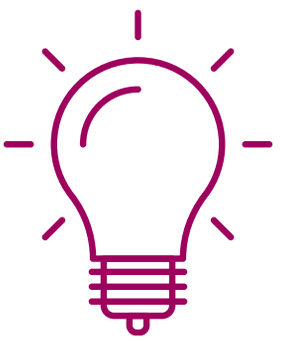
If you find yourself unable to manage, you may need to take yourself out of the environment for a short period of time.

Talking about overwhelming anxiety with family and friends can be comforting. You may also find it helpful to share with others like a GP, psychologist, counsellor, clergy member, or your Dementia Adviser.

Support groups for carers and for those with dementia can connect you with others in the same situation, as well as providing information. You can find local dementia-friendly groups on our website.
www.dementiaoxfordshire.org.uk/events

Comprehension and understanding

Like many other aspects of thinking and judgement, changes in comprehension and understanding are common signs of dementia.



About the symptom

A person with dementia may:

- Frequently ask for an explanation of what they have seen, heard, or read
- Have difficulty with activities that involve planning and problem solving, for example, the steps for a task, making a shopping list or performing errands
- Using technology, like remote controls or telephones
- Understanding the passage of time – what has just happened, and/or the reality of how much time has passed

Understanding the symptom

Comprehension is a complex process, which involves recognition, language and judgement, among other functions. Each of these is a complex process requiring multiple brain chemicals that become disrupted in dementia.

People with dementia often have difficulty with planning. The person you care for might know what they want to do and how to do it, but might not be able to put the actions together to perform the task. Sometimes the person with dementia does not understand something that they see or hear. This makes it difficult for them to follow what is happening on a television program or to tell someone about something they are reading in the newspaper.

> “I line Colin’s clothes up from left to right, he will pick up the next piece of clothing and it works well.”
>
> **Kay - Informal carer expert**

Managing comprehension and understanding

Difficulty with comprehension and understanding are common with dementia and can be difficult for both the carer and the person experiencing it. To help everyone involved, try these helpful tips:

Minimise stress

Sometimes the person you care for might find a lot of noise and people to be distracting or even overwhelming. Try and decrease the noise level and the number of people interacting with the person at any one time.

Speak clearly

During a conversation you should face the person directly, maintain eye contact, and speak slowly and clearly. Ask questions that require simple answers and allow plenty of time for response. If verbal communication is difficult, try using picture/cue cards to find out what they need.

Use consistent language

When repeating a question or an answer, try using simpler, shorter words to make it easier to understand.

Avoid disruptive environments

Try to avoid environments or situations that tend to create confusion or uncertainty. For example, if they become confused by something on the television, change the channel or turn off the television and redirect the conversation or activity.

Start activities with the person

If the person you care for is sometimes confused or uncertain about what to do next, start the activity with them and help guide them through the first steps. This can be especially helpful for important but simple tasks, such as personal care and household chores. These can be made easier if presented in a simple, structured and natural way. For example, if they have finished washing their face, hand them their toothbrush to remind them of the next activity.

> “I struggle to work out how to use the TV remote control and mobile phones now - it doesn’t bother me though, Christine does it for me.”
>
> **Glenn - Living with dementia expert**

Disorientation to time

One of the many things that people living with dementia can find difficult is the concept of time. This difficulty can manifest in many ways and can make day-to-day living more challenging.

The ability to tell the time and plan accordingly is a complex process which can be difficult for people with dementia. Their natural circadian rhythms can be off-balance, so they don't instinctively know what time of the day it is, whether it's night or day, or what season it is.

About the symptom

A person with dementia may:

- Be unable to remember dates and times and may not know the day, week, or month
- Need to rely on calendars or aids to keep track of appointments and special occasions
- Refer to past events, places and people in the present tense or think something that just happened took place a long time ago (e.g. mix up living relatives with those deceased)
- Experience difficulty judging the passage of time and may confuse day and night

Understanding the symptom

Issues with memory play a large role in why people with dementia lose track of time. If they're having trouble remembering events as recent as a few minutes ago, they might not have perspective of when other events happened, or will happen, in comparison. It's like trying to find directions on a map when you don't know where you are to begin with, but with time.

People with dementia can also lose their ability to understand how much time has passed. They might think that you haven't spoken to them for weeks, when you do so every day. Or perhaps they insist that they went out with their friend yesterday, when in fact it was months ago.

Managing disorientation to time

> “I use the television or the radio as my gauge to take me through the day. You know how long Woman's Hour is, or you know the one that comes at 12:45 is only 15 minutes, and that all gives me a good idea of where I am in the day.” **Marianne - Living with dementia expert**

Disorientation to time can be frustrating for both you and the person you care for. These tips can help:

Help the person understand their day

A whiteboard listing the day, date and planned activities or appointments will help the person you care for understand their day. Discuss their daily schedule as well to help the person you care know what to expect.

Establish a schedule

It may help to create an established schedule of activities. This gives routine for the person you care for. The routine helps them better judge the passage of time and be better aware of the time of day. Allowing them to sleep all day may make it difficult to tell day from night. Instead, consider including exercise in their daily routine, particularly in the morning or early afternoon. This will help them to sleep at night.

Increase awareness of time and date

Make it a habit to speak of the day, month and time each day. Hang a calendar by the bed or in the bathroom to help orientate the person you care for and encourage them to check off the days.

Create a memory book

A memory book can help prompt memories of family, friends, and special occasions. It could contain photographs of people identified by time, place and date, e.g. write the names, birthdays and wedding anniversaries underneath the appropriate pictures and review the book on a regular basis.

> “He’s relearned a lot of things through repetition – he will ask what day it is, and I’ll say “look at your watch” so now he just looks at his watch. We changed his watch to a simple digital watch, and he can tell time on that much easier.” **Informal carer expert**

Social interaction and withdrawal

Often dementia can affect parts of the brain responsible for social interaction. Problems such as social withdrawal often occur early in the condition and worsen over time. Inappropriate behaviour with other people can also be a problem.

About the symptom

A person with dementia may:

- Socialise less, even with people they have known a long time
- Withdraw from social activities in which they used to regularly participate
- Have a loss of inhibitions, sometimes causing them to act inappropriately

Understanding the symptom

People with dementia often socialise less with friends. One reason the person you care for might be reluctant to meet with friends is embarrassment because they cannot remember names or faces, or because they can't follow conversations. They may also be disorientated by changes in the setting. However, you may find that the person you care for is happy to continue to take part in activities that stay largely the same each time, such as religious services and shopping.

A different challenge is when someone you care for loses their inhibitions. They may forget how to behave in a social setting and may say or do things that are inappropriate and cause offence. This can be challenging both for them and you. It's likely that the person with dementia does not recognise their behaviour as being inappropriate and can become confused and agitated when told to stop. It's possible that they have misunderstood someone else's behaviour and have responded accordingly. Alternatively, they may be expressing a need for affection. It's also possible that they have mistaken the person they are interacting with for their partner.

Managing social interaction and withdrawal

Sometimes the person you care for might withdraw from a social activity because they do not have the initiative to undertake it. Even so, they might still be interested in the activity if you were to take them to it. As dementia progresses, you may find that both initiative and interest decline, so even if the activity is started for them, they still aren't interested. This can be upsetting for everyone involved. To learn more about what to expect and how to deal with this symptom, try the following:

Look into adult day programmes

If the person you care for is becoming less involved in social activities, look into local adult day programmes, where activities are organised and a meal provided.

Other ways to contribute

The person you care for might not be able to follow the discussion in a group or organisation, but they might be able to help in other ways, such as helping to make the teas and coffees. This allows them to continue to contribute to the group.

Stay with them when possible

In order to reintroduce past social activities, offer to stay with them. Providing a familiar face and support may give the extra confidence needed to resume activities they once enjoyed.

Group vs. one-on-one

Many people with dementia find large groups confusing and cannot follow the conversation in the midst of noise and distraction. One-on-one activities can be more successful. A visit may include a short stay involving simple conversation and perhaps a gift of food.

Make social situations comfortable

If the person you care for is withdrawing from friends and family, it could be because they cannot remember names or recognise faces. If so, you can let friends and relatives know of ways to make the person more comfortable, such as telling them to introduce themselves and to suggest topics which you know that the person you care for can discuss. Friends can also learn to not ask 'how are you?', but to say 'its good to see you' as a way to open conversation.

Tips for dealing with inappropriate behaviour:

Have a conversation

Talk to the person with dementia about their behaviour calmly, in private and without accusations. They may be able to offer an insight into how they are feeling and the need they are trying to meet through their behaviour.

Look for signs

Take a step back and see if there was anything that prompted this behaviour. Did the person with dementia misinterpret something and then respond in a way that they felt was acceptable in the situation?

> "You have to get out and about and meet people – socialise – spend time with other people. There are so many memory cafes out there, and they're all different. There's bound to be one you like and talking to other people that understand is fantastically important."
>
> **Brian - Living with dementia expert**

Irritability and frustration

People with dementia can become easily frustrated or irritable. The reason for this is not based in memory loss, but personality and behavioural changes and lack of insight into why carers are trying to control their environment. It is helpful if the carer learns to detect the early signs of frustration and agitation before it escalates.

About the symptom

A person with dementia may:

- Become agitated at reminders that their abilities are declining (e.g. when unable to complete a task because of memory problems)
- Become frustrated when they need assistance with tasks previously done independently
- Resent the carer
- Become irritated because they dislike being told what to do
- Appear argumentative and critical of others

> “Don't keep it to yourself - talk to a friend. Don't just keep it bottled up inside. I think that would be the worst thing to do.”
>
> **Christine - Informal carer expert**

Understanding the symptom

Irritability has many causes, but it often reflects damage in a part of the brain known as the frontal lobes. In the past, frontal lobe impairment was seen as a late sign of dementia, but the thinking surrounding this has changed. Now that there is better testing of the frontal lobes, we see that this area of the brain is involved much earlier in the progression of dementia. Also, brain imaging studies suggest that early on in dementia, the brain is able to find ways to work around frontal lobe damage. However, it suggests that the ability to do this lessens as the condition progresses. This is an important insight for researchers who are exploring treatments for dementia.

Managing irritability and frustration

Irritability and frustration are very common in early dementia. This can be distressing for families, especially when it is out of character. It is important to know what to expect and how to deal with this difficult symptom, which is why these management tips can help:

Eliminate triggers when possible

If there seems to be a common thread in what triggers the irritation or outbursts, try to eliminate these triggers whenever possible. For example, if remembering telephone numbers is difficult, make sure common numbers are stored in the phone's speed dial option .

Discuss the issue with them

Beginning a conversation with the person when they become agitated may help to relax some individuals with dementia. Try to talk about the underlying cause of the agitation and be empathic to their responses too. Validating peoples feelings lets them know you are supportive and understanding.

Offer encouragement

Try to encourage the person you care for to do activities that they enjoy and are good at. In many cases, this will make them less likely to become frustrated and give up.

Consider the amount of stimulation

Too much or too little stimulation can lead to irritability. If you feel there is too much stimulation, you might try calming strategies or distraction techniques such as music, a particular television programme or a particular food. In the case of too little stimulation, offer the person you care for a purposeful activity such as folding laundry, rearranging books, or going for a walk.

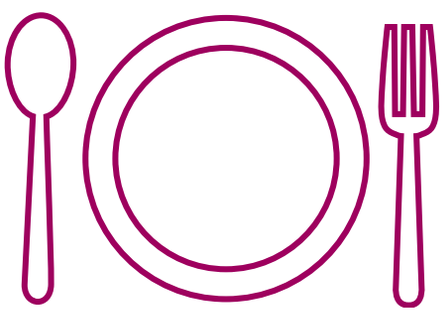
> “Negative memories can stay with him for weeks – he has a tendency to hang on to the negative. Something can prompt him to recall the memory and that's where it starts.”
>
> **Informal carer expert**

Difficulty with everyday tasks

Dementia can affect a person's ability to make multiple decisions, one after another. This can affect many tasks that require a sequence of actions. Meal preparation and cooking are good examples of this type of task, but the advice here could apply to other tasks too, such as getting dressed.

About the symptom

A person with dementia may:



- Be reluctant to undertake a task with several steps. They may eat simple meals or wear the same clothes repeatedly
- Demonstrate behaviours that are safety concerns, due to memory loss or decreased attention span
- Require assistance in certain aspects of the task

Understanding the symptom

There are many reasons that a person might have difficulty in tasks such as preparing a meal. Usually, the problem is not one of forgetting how to mix ingredients together, stir a pot, or crack an egg. These skills are known as procedural memory and will often be well preserved. Many people with severe dementia can still complete single-task chores.

The problem with complex tasks in mild dementia comes from damage to a part of the brain that controls executive function. This means the person with dementia may lack motivation (to get started), insight (to understand issues such as timing), the ability to sequence (to decide which step comes next) and also to plan ahead (what the end result should be).

> “Marianne gets a bit anxious before her work days, so I get everything out the night before. She makes her own sandwiches, but I get everything out and put it on the side. I am not doing it out of duty or to be an amazing bloke. I'm doing it because if I help Marianne, we have a better time.”
>
> **Ieuen - Informal carer expert**

Managing everyday tasks

Although it can be difficult for all involved, when the person you care for has trouble with everyday tasks, there are a few tips you can try:

Plan accordingly
Plan the activity in advance and offer assistance throughout when possible.

Label clearly
Use labels on drawers and cupboards to help the person know where to look for items. If the task involves cooking, make sure the on/off switch positions are easily marked on all the appliances.

Prepare the space
Lay out everything that is needed before you start and ensure there is enough time to complete the task without rushing.

Get help when you need to
If the tasks are becoming too difficult, look at how you might get help. If cooking is a problem for example, there are companies who will deliver nutritious frozen food that can simply be put in the microwave.

Get them involved
Ensure there is part of the task that the person you care for can do (e.g. peeling vegetables or sorting washing into different colours). Feeling involved and helpful will help to improve feelings of confidence and self worth.

> “I find the more I know about dementia, the less frightened I am of it.” **Glenn - Living with dementia expert**

Listening to our experts

Our Experts by Experience are people with lived experience of dementia. Some of them have a diagnosis, some care for loved ones. As well as helping with the design of this booklet and our Information Sessions, they often undertake training with local hospital staff, to improve the hospital experience for anyone with dementia. They have also provided feedback on a new dementia app, sat on an interview panel for the Dementia Lead Nurse at the John Radcliffe Hospital and taken part in a round table discussion about dementia on BBC Radio Oxford.

Their conversations are always inspiring.

Slowing down helps – I keep going but at my own pace

We laugh a lot. I think we've always, as a family, liked to laugh. We're not afraid of looking at difficult things. But then I think that gives you space to laugh then, doesn't it?

Being a carer for someone you love is really hard. It's normal to struggle sometimes.

You absolutely have to continue to live your life the way you want to and do things that you really want to do. And I mean, the fact that you can still do this really really has to tell people that a diagnosis of dementia is not the end and full stop.

I'm not going to become competent at new things at this stage in my cognition, but there are things which I can continue to do and enjoy.

Keeping well and slowing progression

Recent research has identified several modifiable risk factors for dementia. These are things that you can change or avoid to reduce the risk of developing dementia. There is also good evidence that addressing these factors can help slow progression of symptoms even after a diagnosis.

Hearing

Hearing loss is considered one of the most significant factors in the development of dementia. Even after a diagnosis, it's very important to have regular hearing tests and to wear hearing aids.

Eyesight

Poor eyesight can also have an effect on how effectively the brain is able to process information. A regular eye test will keep glasses prescription up-to-date and also detect any new eye conditions.

Healthier heart = healthier brain

High cholesterol, high blood pressure and carrying extra weight are known to put to strain on your heart. Research suggests that these factors may also affect the health of the brain, so sticking to a healthy diet is important. Regular check ups with your GP will keep medication up to date.

Social connection

Staying socially connected is vital for everyone as we get older, but has shown to be especially important for people with dementia. Social interaction can seem daunting, but is good for the brain and can greatly improve mood.

Physical activity

Exercise improves blood flow to the brain and releases chemicals that make us feel happier. A brisk walk in the fresh air every day can make a real difference. Exercise can also help with depression, which is sometimes a symptom of dementia.

Smoking and drinking

GPs can help with ways to stop smoking or cut down on excessive alcohol consumption. The NHS suggests no-one should drink more than 14 units a week, the equivalent of 6 pints of medium strength beer or 6 medium sized glasses of wine.

Notes

Notes

How to contact us

We're here to help you care for someone living with dementia. Your designated Dementia Adviser will be happy to help you. Please do contact them when you need information, advice or support.

You can also call our support line, open from 9am to 5pm, Monday to Friday.
Support Line: 01865 410 210

The support line is staffed by Dementia Advisers who offer advice and guidance to everyone, including people with dementia, their relatives, carers and healthcare professionals.

If you'd like to see what dementia-friendly events are happening near you, you can visit our website.
www.dementiaoxfordshire.org.uk

Dementia Oxfordshire

A service provided by Oxfordshire age UK

This booklet has been co-produced by our Experts by Experience, a group of people living with dementia and their informal carers.

If you would like to join our group of Experts by Experience, whether you are living with dementia or a carer for someone who is, do get in touch. We'd love to hear from you.

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