A straightforward guide to dementia

Understanding and managing symptoms and behaviours

Dementia Oxfordshire

A service provided by

Oxfordshire age UK

Contents

Foreword

At Dementia Oxfordshire, we developed our educational offer in an interactive way, consulting people with lived experience and taking feedback from session participants. As we progressed, it became clear that there was a need for some written material that people could take away and refer to later. The result is this guide, it builds on the work of others which we then tailored to align with the educational sessions we run.

I hope this guide is useful, not just as a complement to our sessions, but as a stand-alone reference that people with a diagnosis and unpaid carers can dip into as the need arises.

Living with dementia can be lonely and isolating. I want this guide to help people understand they are not alone, and that finding a community of people that you can share experiences with helps make it possible to live well with dementia.

Peter Johnson
Head of Dementia Oxfordshire service

Introduction

At Dementia Oxfordshire, we work closely with those living with dementia and their informal carers, easing the impact that a diagnosis and symptoms can have by offering ongoing support. We know that with better knowledge of dementia comes a better understanding of how we can support those living with the condition.

The Dementia Oxfordshire Team

As Dementia Advisers, we know that both the person with dementia and those who support them are equally important. As an informal carer, your wellbeing is interlinked and how each of you feel at any point of any day will affect the other. There will be good moments, where there may be fun and laughter, and there may be bad moments, with frustrations and low mood on both sides. Just know, that none of you are alone in this.

Our experts tell us that it is important to work together, and, if you can, to try discuss symptoms and work in partnership to support each other. We know how difficult it can be to talk about dementia and some people may even find it upsetting.

Our approach realises that each person is unique, so our advice and support is just as unique. Whatever people living with dementia and informal carers are experiencing, we are here to listen.

This booklet has been co-produced by our Experts by Experience, a group of people living with dementia and their informal carers. Together, we've explained some common symptoms that people living with dementia may experience, offered an understanding of these symptoms, and how some of our informal carer experts respond to these symptoms. By attempting to understand dementia, we have the best chance of supporting the person and those caring for them.

This booklet draws on the information leaflet produced by Dementia Link.

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

Repetitive questioning is often misunderstood as a need for information. In fact, recent medical studies have found that the use of repeated questions may often be a call for reassurance, to be involved or be heard.

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 tasks in a logical sequence.

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

You may recognise the underlying reason for their questions. For example, if they are asking what time it is, could the time reflect something important they used to do, e.g. pick their children up from school, go to work, or an upcoming appointment? If you can identify the cause, it can be easier to reassure the person, e.g. '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 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 new activity. Could you share a story about or do a topic of interest. 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 an erasable whiteboard. Or on a notepad in a place you know will be visible throughout the day. The person you're supporting can better understand their day if you discuss the daily schedule, as well as display it.

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**

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 is what most people think about when they think about dementia. However, the impact on memory changes can vary depending on the type of dementia. Some may forget or deny that they have a dementia diagnosis or might not recognize 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 e.g. 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 forget things all the time, and my brain is just blank when I think about what I've just done – and that can make me feel worried. I'll notice that the shed is unlocked, and I know I must have been in there because I always keep the shed locked. Then the memory will start coming back to me when I get that prompt, but it doesn't always happen.
>
> **Philip - 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 part, 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

Get their full attention, face the person and make eye contact. Speak in a soft, calm voice, avoid using lengthy verbal instructions and complex vocabulary.

Break up information

Break instructions into step-by-step tasks that can be completed individually (written out if they can understand what they read).

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 showing a picture of the item itself to gain a response.

> “ 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.
> **Kay – Informal Carer Expert**

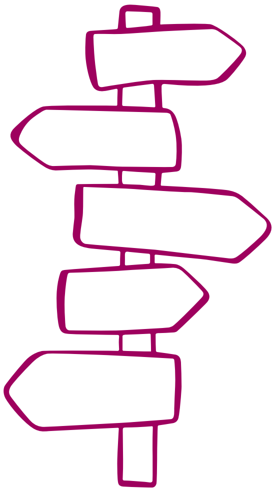
Loss of initiative

Loss of initiative can be challenging for families as the person with dementia may lose insight and motivation. As a result, their families are required by circumstances to find new ways to stimulate the person and encourage activities of interest. This can help prevent the person from being disengaged.

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 (e.g. 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 sometimes is present before the diagnosis of dementia, it generally occurs in early dementia and becomes worse as the condition progresses.

Loss of initiative can be seen in many ways. It can be the person telling you that they are unsure of what to do next or need 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.

> My husband has a loss of initiative at times, and he relies on me for this, which can be very hard. **Informal carer expert**

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

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, although 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.

Bring social life to them
Invite friends or relatives over. This might encourage them to go visiting next time. Simply going for a drive can be stimulating.

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 troublesome when associated with suspiciousness.

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 neurological pathways that allow for such a complicated memory task can be damaged.

Think about memory like putting things 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'.

> “ David can forget where he parked - he goes around the car park looking for it until he finds it. Sometimes he can't see it even when he's looking at it - he may have forgotten what he's looking for. **Informal carer expert**

Managing misplacing or losing objects

> “Be careful when reducing clutter, one may be accused of disposing of something that was important. I have found it better to use a gradual approach rather than having a good clear out all at once. **Informal carer 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 available:

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 primary 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

Particularly 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

Such as toothbrushes, keys and pens. 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 irreplaceable and 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.

> “He always claims that it is me who has mislaid or lost the item!
> **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 offer a sense of ease.

About the symptom

A person with dementia may:

- Experience anxiety about not being able to do what they used to be able to do
- Be afraid of missing appointments or remembering important dates
- Worry about being separated from their carer for security (e.g. upset over when the carer is scheduled to return)
- Express concerns about their future (e.g. progression of the condition, new situations)

> “ Something prompts him to recall a negative memory, and that’s where it starts.
> **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. Sometimes medication used to relieve anxiety can make other symptoms of dementia worse. For this reason, treating symptoms of anxiety and worry in dementia must be done cautiously. On occasion 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 white boards to list weekly activities to remind them. If they are often worried about a task which has already been completed, include a place on the white board 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 is common and 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 and provide 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 judgment, 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 involving planning and problem solving, e.g. 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 taken place

Understanding the symptom

Comprehension is a complex process, which involves recognition, language and judgment, 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 cannot 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.

Managing comprehension and understanding

> 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**

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 their need.

Use consistent language

When repeating a question or an answer, try simplifying your response 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 initial 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, the 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 lose orientation for 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 comprehend 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

> D struggles to remember which day it is and what he’s doing. He relies on me and it can feel suffocating. **R - Informal carer 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 for feel orientated.

Establish a schedule

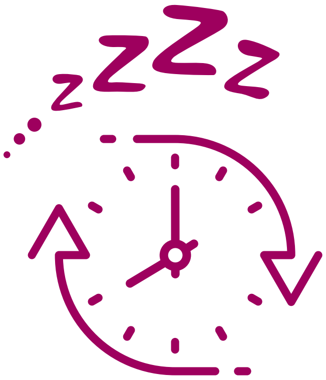
It may help to create an established schedule of activities. This gives routine for the person you care for. The routine helps them better judge the passage of time and be better aware of the time of day. Allowing them to sleep all day may make it difficult to tell day from night. Instead, consider including 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 orient the person you care for if they habitually check off the days.

Create a memory book

A memory book can help keep the 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 conduct with others can also be a problem.

About the symptom

A person with dementia may:

- Socialise less, even with people they have known a long time
- Involve themselves less or 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. Another is that the condition can affect the parts of the brain involved in initiative and social conduct.

When the person you care for is withdrawing from activities they previously enjoyed, their reluctance could be due to fears of being unable to remember names or faces, or the inability to follow conversations. Additionally they may worry about new changes even in a familiar setting. You may find that the person continues to participate in certain activities such as religious services, shopping, and small group functions because of consistency and familiarity.

When someone you are supporting loses their inhibitions, they may say or do things that are inappropriate and can 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 misinterpreted someone else's behaviour and have responded in kind. In fact, they may be expressing a need for affection or confuse the person with whom they are interacting with as being 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. Later, however, both initiative and interest decline, so even if the activity is started for them, they may want to withdraw from it. 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 adult day programmes. It‘s important that there’s enough people at their ability level in the programme and coordinators will ensure those who require extra time and attention receive the needed care.

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, allowing them to still 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 identify them. 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 from their behaviour.

Look for signs

Take a step back and see if there was anything that prompted this behaviour. This could be something that the person with dementia may have misinterpreted and so is responding in a way that is normal for the situation as they see it.

> “ I still sing with the Barber Shop Choir. It’s the togetherness that brings me joy. For the few moments we’re singing together, we are a unit, we lean on each other and support each other. I remember the songs easily, but new songs can be tricky. **Colin - 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 early 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

> “ Becoming upset or annoyed when the person you care for is having difficulty remembering something will only add to their frustration. Try to stay calm and patient with them.
>
> **Informal carer expert**

Understanding the symptom

Irritability has many causes, but it often reflects impairment in 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, the brain is able to compensate for frontal lobe damage. However, it suggests that the ability to compensate diminishes as the condition progresses. This is an important insight, because strategies to treat dementia should not just focus on countering the condition’s progress, but should also enhance the repair process.

Irritability can also be a state that is accompanied by anxiety and depression. As such, people with dementia can respond to specific treatment for depression, especially with drugs that increase the level of a neurotransmitter called serotonin. Although many physicians will attest to this, demonstrating the existence of a syndrome of 'Dementia Associated Depression' has been difficult and so too has been the effect of treating it.

> I still feel responsible for my wife, even though I have dementia. I want to look after her, so I feel upset when I can't do this. **Living with dementia expert**

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 troublesome, aids such as speed-dial may alleviate the problem for a while.

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.

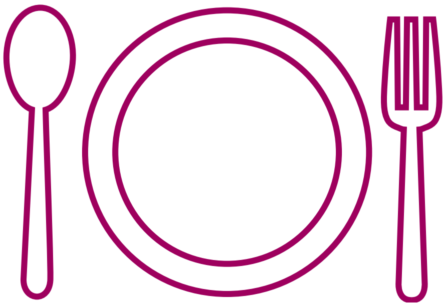
> Negative memories can stay with him for weeks – he has a tendency to hang on to the negative. Something can prompt him to recall the memory and that's where it starts.
>
> **R - Informal carer expert**

Meal preparation and cooking

Dementia can affect a person's ability to make multiple decisions, one after another. This type of decision-making is needed in order to prepare food from ingredients.

About the symptom

A person with dementia may:



- Have a low motivation to cook, so that they tend to prepare simple meals that involve minimal cooking
- Demonstrate behaviours that are safety concerns, due to memory loss or decreased attention span
- Require assistance in certain aspects of meal preparation

Understanding the symptom

There are many reasons that a person might have difficulty in preparing a meal. Usually, the problem is not one of forgetting how to mix ingredients together, stir a pot, or crack an egg. These are highly learned motor behaviours that are known as procedural memory and often will be well preserved. Many people with severe dementia can still complete single-task chores. In mild dementia, people can lack the motivation to actually start the task, the insight to know that it is time to get started, or the ability to plan what should be served. They can also have difficulty remembering which things on the list have already been done.

These complex behaviours often reflect problems with planning, sequencing, insight and judgment, which are known as executive function. This is because people who have localized damage to their frontal lobes (say from a car accident, or blood vessel problem), characteristically have problems with executive function.

Managing meal preparation and cooking

Although it can be difficult for all involved, when the person you care for has trouble with meal preparation and cooking, 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 and ingredients. Make sure the on/off switch positions are easily marked on the all appliances to help make the positions clear.

Prepare the kitchen

Lay out the ingredients and utensils for the project and ensure enough time to complete.

Get help when you need to

Consider assistance services if cooking has become too problematic and burdensome. These programs often deliver healthy frozen meals, which require only a microwave to prepare.

Get them involved

Ensure there is part of the meal preparation that the person you care for can do (e.g. peeling vegetables). Feeling involved and helpful will help to improve feelings of confidence and self worth of the person.

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

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

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Acknowledgements

This booklet has been co-produced by our Experts by Experience, a group of people living with dementia and their informal carers. Together, we've explained some common symptoms that people living with dementia may experience, offered an understanding of these symptoms, and how some of our informal carer experts respond to these symptoms. By attempting to understand dementia, we have the best chance of supporting the person and those caring for them.