



Belfast Health
and Social Care Trust

Dementia and Behaviour: Memory and Forgetting



Information for carers

Community Mental Health Team for Older People

We hope this information helps you understand changes in your relative's behaviour due to dementia, and that you find some tips that work well for you both.

Share the tips that worked with family, friends and others who spend time with your relatives; it will reassure them that they are doing all they can for both of you - give them this booklet to read or go through it together.

We have booklets on many other changes in behaviour that may occur due to dementia and would be very happy to share them with you.

Please call us on: 02895040346

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Memory

All the bits of information that make up a memory are put together in the brain - what we see and hear, how we feel at the time, etc. Each new memory is learned in this way, and the brain then files it away to be remembered later.

Most of the time our brains are doing this without us paying any attention to it - memories for what we talked about this morning, did last week, or events throughout our lifetime such as a weddings, who we meet etc. However, we can all think of times when we have had to use a lot of our thinking skills, to learn something - learning how to tie our shoes took time, ability to think well, concentration and practice.

When put into our memory files, our brains are also very good at recalling all the bits of the task or event so quickly and in the right order that we remember it without even thinking about it!

From when we get up in the morning until we go to bed at night we rely on our memory for almost everything we do. For example, in order to get up on time we have to remember to set an alarm clock the night before. In order to set the alarm we need to remember what 'time' actually means, how to set the alarm and what time to set it for. We need to remember that when the alarm goes off this means it is time to get up.

When we get up we need to remember where the bathroom is so that we can go to the toilet and get washed and we need to remember that we have to put on clean clothes. We must also remember where the clothes are kept and on which parts of the body they are worn.

When we go for breakfast we need to remember where the tea or coffee is kept, where the cups, kettle and milk are and then we need to remember how to put all this information together just to make a cup of tea. We haven't even had breakfast yet and look at all the tasks that have relied on our memory!



Memory and Dementia

Dementia is an illness that affects the brain and because of this the brain doesn't work as well as it used to. Because memory uses many processes that can be affected by dementia, there are various ways your relative may be affected and you may recognise any of these:

Your relative's ability to learn new tasks may lessen:

- Their ability to think about things has reduced and they may not be as able to work through the steps of a new task as well as they once did; this can mean they may not be as able to learn how to work a new TV etc. This can be frustrating for your relative as they may see this as a simple task and know they were able to work the old one.
- They may be less able to put new memories into their memory store. Therefore, a conversation, or a family event or indeed how to work the new TV has not been put into their memory store and is not there to be recalled or remembered at a later time. This can mean your relative may not remember a conversation, a person they met, or what they may have been doing earlier in the day. This also means your relative can become repetitive and ask the same question or tell you the same thing, or do the same thing again and again.

Your relative's memory store is being affected:

- Your relative may be losing memories over time - this usually happens from the most recent memories through to those that have been in memory for a long time; you might find that your relative can remember lots from the past, but struggles to remember what happened earlier in the day, last year etc.
- Your relative's ability to search through their memory store and find the right conversation or event has been affected. They may bring a different memory to mind and you may find they get conversations, people or what they are doing mixed up.
- When your relative's memory has gaps or is patchy they may try to fill these with pieces of other memories so that the situation makes sense to them. This does not mean that they will make sense to you though, and your relative's behaviour can be puzzling and sometimes difficult for you, and others to understand.

It is important to remember that any changes in your relative's behaviour are because of their dementia. Whilst being repetitive or forgetting something that was talked about earlier can be frustrating or upsetting for you and others, your relative is not intentionally behaving this way.

In the early stages of dementia your relative may try to cover up problems with their memory as they may feel embarrassed, distressed or worried what this may mean. Also, as memory difficulties become more apparent, they may feel more lost and anxious. You are also likely to be anxious and worried about what this may mean for you both.

It is important to remember that memory loss will usually happen very gradually over time and that there are practical things which may help your relative maintain independence for as long as possible. There are also many things that can help prevent and reduce any upset and distress, resulting from memory difficulties.

This booklet will look at some of the most common memory difficulties, and give tips that others who care for someone with dementia have found useful.



Difficulties learning new information

Problems with memory and thinking can make it difficult for a person with dementia to learn new information and the ability to do so deteriorates over time. Therefore, if you change your car your relative may struggle to recognise it. If there is a new TV or radio your relative may have difficulty working out how to use it or perhaps can manage one step only, for instance the on/off button. Sometimes, practice will help, however, for many people it won't and they may get frustrated.

What can help

- If your relative needs you to operate a new TV etc, this can mean they may interrupt what you're doing, and means another task for you to do. It is important to remember that this is not because they are being lazy; indeed it is likely to be frustrating for them. Understanding this means you can perhaps help them before they, or you, become frustrated.
- Making learning as easy as possible will make the most of your relative's ability. Try the following tips:
 - ♦ Be patient with your relative, try not to rush them.
 - ♦ When your relative is trying to learn something new, it will help if there are as few distractions as possible. Try and do so in a quiet place and clear the surrounding space, this will help them to concentrate.

- ◆ Break tasks up into small steps and take each step one at a time. This will help your relative to focus and remember what they have done and what comes next.
- ◆ You can try writing the steps down and ticking them off as you go. Indeed, it may be useful to keep this and use it over time to help memory become established.
- ◆ Keep information straightforward and repeat it to give your relative the best chance of taking it on board.
- ◆ Pictures and gestures can sometimes be useful.
- ◆ Avoid putting pressure on your relative, as failure can often make us feel useless, distressed and frustrated.



Asking questions, being repetitive

One of the most common changes in behaviour connected to memory loss is when someone becomes repetitive (asking the same question, telling the same story or doing the same thing again and again). This is something that carers tell us is difficult to deal with.

There are a few different types of repetitive behaviour. Your relative may do one, some, or all of these:

- **Asking the same question** - “Where am I?” “What are we doing now”?
- **Telling the same thing**- for example telling you the same story over and over.
- **Doing the same thing** - for example repeating kitchen tasks or going in and out from the garden to brush up.

Many people with dementia can ask the same question or tell you the same thing again and again. It can be quite difficult for you and others to understand why, and also quite tiring to listen to.

Some of the reasons include:

- Your relative forgets having previously asked the question or having told you
- They forget the answer

- They are feeling anxious about where they are, why they are there and what they should be doing and they are looking for reassurance. Indeed they may forget that they have been reassured and look for it again.
- Your relative may need something else and is unable to think about or let you know what it is they need.



What can help

- Reassure your relative and let them know you are there for them.
- If your relative has difficulty letting you know what they may need, check that they are comfortable. Are they hungry? Thirsty? Been to the toilet recently? Are they warm enough?
- Memory aids such as calendars, clocks or whiteboards are useful to display a routine for the day, or you may write down the answers to any questions your relative may be repeating.
- It can help to have personal belongings within your relative's sight or reach to remind them of where they are and to lessen any anxiety.
- Get your relative involved in enjoyable activities such as going for a walk, gardening or household chores.



- Avoid telling your relative that they have already asked the question, or that you have already answered it. Your relative will not have remembered this and it may make them feel anxious or perhaps frustrated as for them this is the first time they have asked.
- If your relative is asking to go home when they are already in their own home, try not to correct them as this may cause distress. Instead let them know they are safe with you and that you will look after them. (You may find another of our booklets useful: **Misinterpretation, mixed up, or muddled.**)
- Getting a foot or hand massage can be very relaxing for all of us and can provide comfort for your relative.



Sometimes a person with dementia can do the same thing again and again because they have forgotten they have already done it. Your relative may buy the same thing in the shop every day, they may do the same laundry several times, or forget that they have taken the dog for a walk and want to go again. Indeed they may forget that they have eaten and prepare another meal.

What can help

- Provide a checklist that your relative can use to tick off tasks that have been completed, this can also be used as a reminder of things that still have to be done.
- Encourage your relative to use shopping lists when they go shopping.
- Reassure your relative that the task they want to repeat can be done later and ask them to help you with an alternative one.

Difficulty remembering people, places and events

Many people with dementia experience difficulties remembering people, places and events:

- They may forget what people or places look like, and they can even forget what they themselves look like. For your relative this means they are talking to or being with strangers and this can be distressing for all concerned.
- They may not remember what has happened earlier, or what they have done earlier. For example, the person with dementia may put their purse or wallet down and then forget where they put it. At times this may lead to disagreements and bad feeling, as for your relative the only explanation is that it must have been taken from them.

What can help

- Try to avoid asking questions such as “Do you know who this is?” or “Where did you put the...” as this will put pressure on your relative who may then become defensive.
- If your relative has problems remembering places or finding their way around, encouraging them to go out with you, another member of the family or a friend will prevent them getting lost. It can also be helpful to encourage them to carry identification.

- Encourage people to introduce themselves to your relative. Alternatively you can introduce others to your relative by saying something like “Look, Alice from next door to see you”.
- If your relative gets names wrong it will not usually be helpful to correct them. We can all make this mistake sometimes and your relative is less likely to feel bad about themselves if you make light of any mistakes.
- Having a regular routine will help your relative to remember what is happening that day as well as providing them with some consistency. Write up a daily schedule and keep it somewhere your relative will see it. Try sticking it to the fridge or even writing it on a white board and hanging it on the wall.
- Encourage your relative to go to bed at night and get up in the morning at the same time every day, as this can help to structure their day. However your relative’s sleep patterns may change over time due to their dementia and may need adapted to.
- It is always easier to find a particular thing when we are looking in a tidy and organised room. Keeping the house tidy and just being as organised as possible can help your relative see what they are looking for – this can reduce the chances of becoming frustrated if they can’t find something.
- ◆ Keep surfaces as clutter free as possible so your relative can find things easily and so their house remains as familiar to them as possible.

- ◆ It can be useful to put things on shelves rather than cupboards or behind doors, and keep in plain sight.
- ◆ Put a calendar on the wall and write any appointments in it. Encourage family, friends and other carers to use it as well.
- ◆ Put coats, umbrellas, hats etc close to the front door to be collected on the way out. Similarly if there is a bag or package to be taken keep this by the door.
- ◆ If your relative struggles to remember where they have left things try to encourage them to use one place for keeping possessions. A large glass bowl on the table for keys, glasses etc. can make it easier to find things and, being glass, it will also be easier to see what is in it.

Caring for yourself

All of the information in this booklet may make caring for your relative easier, but your well-being is just as important. You will find it easier to look after your relative the way you want to if you can get regular breaks. Ask friends and family to keep your relative company whilst you look after yourself, they will want to help.

If you have been caring for a while it might be hard to think of what you would do if you had a break!

What can help:

- Catch up with some friends
- Go shopping for yourself
- Go for a walk
- Go for a relaxing bath



USEFUL CONTACTS

Age NI Advice Line

0808 808 7575

www.ageuk.org.uk

Alzheimer's Society

(028) 9066 4100

www.alzheimers.org.uk/northernireland

CAUSE

(families, partners, friends caring for mental health)

0845 6030 291

www.cause.org.uk

Lifeline

0808 808 8000

www.lifelinehelpline.info

MindWise

(028) 9040 2323

www.mindwisenv.org

How to contact us:



Community Mental Health Team for Older People Tel: (028) 9504 0346

operates from Monday to Friday
9am to 5pm

We also offer an extended telephone advice
and support service for people living with
DEMENTIA and their carers operating:
Monday to Friday until 8pm
Saturday to Sunday 10am to 2pm

If you need to speak to someone
outside these hours please contact:
Regional Emergency Social Work Service
(028) 9504 9999

[www.belfasttrust.hscni.net/services/
CommunityMentalHealthTeams](http://www.belfasttrust.hscni.net/services/CommunityMentalHealthTeams)

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