

The early stages of dementia



Health and
Social Care

Contents

What is dementia?	3
Your dementia diagnosis	4
Progression of dementia and staying independent	5
Look after your health	6
Maintain a social life	6
Keep active and occupied	6
Self-care	7
Behaviour	8
Sleep problems	9
Mood swings	9
Repetitive behaviour	9
Distressed behaviour	11
Becoming suspicious of others	12
Drug treatment for dementia-related behaviour	12
Communicating with people with a dementia	13
Encouraging someone with dementia to communicate	13
Communicating through body language and physical contact	14
Listening and understanding	15
Treatment and support	16
Medicines to treat dementia	17
Antipsychotics	17
Antidepressants	18
Psychological treatments for dementia	18
Cognitive stimulation and reality orientation therapy	18
Validation therapy	18
Behavioural intervention	19
Planning for the future	20
Enduring power of attorney	20
Financial matters	21
Driving and dementia	21
Seeking support	21
After a diagnosis, who can help?	22

What is dementia?

Dementia is a common syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. Dementia can affect anyone, but your risk of developing a dementia increases as you get older, and the condition usually occurs in people over the age of 65.

The most common causes of dementia include conditions where the brain cells degenerate and die more quickly than they would through the normal ageing process.

This damage leads to a decline in a person's mental and, sometimes, physical abilities.



Your dementia diagnosis

Even if you have suspected for a while that you or someone you love might have a dementia, the diagnosis may come as a shock. Recognising that there is a problem, and discovering the underlying cause of the dementia, is important. This is because it will help guide your choice of treatments and services.

An early diagnosis of dementia may also be beneficial because some causes of dementia are treatable and fully or partially reversible, depending on the nature of the problem. Conditions such as some vitamin deficiencies, side effects of medications and certain brain tumours may fall into this category.

Alzheimer's disease and dementia with Lewy bodies gradually damage the brain. Some medicines have been shown to benefit in Alzheimer's disease and dementia with Lewy bodies. These treatments improve symptoms by making the remaining brain cells work a bit harder. Although they will not cure your dementia, these medications can make a significant difference to your day-to-day living and functioning.

Treating high blood pressure, high cholesterol and poorly controlled diabetes is also important, as is stopping smoking and keeping to a healthy weight. These factors (known as risk factors) all contribute strongly to vascular dementia, and may make Alzheimer's disease worse. Your GP can assess your risk factors, advise if treatment is needed and monitor you.

Medications for other conditions can be reviewed, in case they are having a negative effect on how well your mind is working.

Progression of dementia and staying independent

Dementia can affect all aspects of a person's life and that of their family. If you have been diagnosed with a dementia, or you are caring for someone with the condition, remember there is advice and support available to help you live well.

People with a dementia shouldn't simply stop doing what they enjoy in life; instead, they should try to remain as independent as possible and continue to enjoy their usual activities.

The symptoms of a dementia will usually get gradually worse. How quickly this occurs will depend on the general health of the person with a dementia and on the type of dementia they have.

Over time, people with a dementia will need help to cope at home. It is natural to feel worried about the future, but you are not alone – whether you have a dementia or you care for someone with the condition. Health and Social Care, social services and voluntary organisations can all provide advice and support to help you and your family.



Look after your health

Living a healthy lifestyle is important for everyone, including people with dementia. Eating well and exercising are important for everyone.

Changes in eating habits can occur, particularly if someone with a dementia is struggling to find the words to ask for food, which can result in weight loss and poor nutrition.

Maintain a social life

It's easy to feel isolated and alone if you or someone you care for has a dementia. Keeping in contact with others is good for people with a dementia, because it helps them keep active and stimulated. Some people find it difficult to talk about their own or a family member's dementia, or want to help but don't know how.

If a friend or family member finds it hard to talk to you, make the first move and explain that you still need to see them and tell them how they can help you.

You may also find it helpful to join a local group of people with a dementia and their families. You may not be someone who would normally join a group, but being part of a community of people with a dementia, or a group for families who have a member with a dementia, can be helpful. You can share experiences and gain insight and useful tips from others who are going through or have been through similar situations.

Keep active and occupied

People with a dementia should continue to enjoy their hobbies and interests as much as possible. These activities may keep a person with a dementia alert and stimulated, so they maintain an interest in life.

Don't rule out an activity simply because you or your family member has a dementia. Activities may change as the illness gets worse, but people with a dementia can and should continue to enjoy their spare time.

Practical tips

- Keep a diary and write down things you want to remember.
- Pin a weekly timetable to the wall.
- Put your keys in an obvious place, such as a large bowl in the hall.
- Have a daily newspaper delivered to remind you of the date and day.
- Put labels on cupboards and drawers.
- Place helpful telephone numbers by the phone.
- Write reminders to yourself – for example, put a note on the front door to take your keys.
- Programme people's names and numbers into your phone.
- Install safety devices, such as gas detectors and smoke alarms.
- Put bills on direct debits, so you don't forget to pay them.
- A pill organiser box can be helpful for remembering which medications to take and when.

Self-care

Self-care is an integral part of daily life and involves looking after your own health and wellbeing with the support of those involved in your care. It includes the actions you take every day to stay fit, maintain good physical and mental health, and prevent illness or accidents, as well as the effective care of minor ailments and long-term conditions.

People living with long-term conditions can benefit enormously from receiving self-care support. They can live longer, have less pain, anxiety, depression and fatigue, have a better quality of life, and be more active and independent.

Behaviour

Dementia can have a big impact on a person's behaviour. It can make them feel anxious, lost, confused and frustrated.

Although each person with a dementia handles these feelings in their own way, certain behaviour is common in people with the condition. This includes:

- repeating questions or carrying out an activity over and over again
- walking or pacing up and down
- distress and shouting
- becoming suspicious of other people.

If you are experiencing these kinds of behaviour, or are looking after someone who behaves in this way, it's important to remember that all behaviour is a form of communication and the person is attempting to communicate how they're feeling. A person with a dementia may be less able to tell us what they need or what they are feeling so they try to tell us through their behaviour. They are not being deliberately difficult. If you stay calm and work out why they're expressing themselves in this way, you may be able to calm them down.

If you recognise early warning signs, you may be able to prevent distress. Try to see the world from the perspective of the person with a dementia and think about what they may need. Some people find that a distraction can focus a person's energies elsewhere and prevent them from displaying behaviours that can challenge.

Your doctor may recommend behavioural therapies to help the person with a dementia cope with their feelings. These therapies can be straightforward. For example, the person may behave in a particular way because they're bored and

have built up too much energy, and a routine involving regular exercise could help solve both of these issues.

Sleep problems

People with a dementia often experience disturbed sleep. They may wake up during the night or be restless. These problems may get worse as the illness progresses. People with a dementia may also have painful illnesses, such as arthritis, which cause or contribute to sleep problems.

Some medication can cause sleepiness during the day and interfere with sleep at night. Sleeping pills can be used with care in people with a dementia. However, 'sleep hygiene' measures are best. These rules include having no naps during the day, keeping regular bedtimes and avoiding alcohol or caffeine at night.

Mood swings

People with a dementia can experience mood swings as they cope with the daily challenges of living with their condition. They can feel sad or angry at times, or scared and frustrated as the disease progresses.

If you or a family member have a dementia, you may find it difficult to stay positive. Remember that you are not alone and that help and support are available. Talk to someone about your worries. This could be a family member or friend, a member of your local dementia support group or your GP, who can refer you to a counsellor in your area.

Repetitive behaviour

People with a dementia often repeat questions or carry out certain actions over and over again. This may be due to:

- memory loss
- boredom
- anxiety
- side effects of medication.



If you think the person is bored, try engaging them in an activity they enjoy, such as listening to music. Most people with a dementia feel anxious at some point and will need reassured of your love and support. If you're concerned about the medication the person you care for is taking, contact their GP for advice.

Walking or pacing up and down is common behaviour in people with a dementia. It's very common for people at certain stages of dementia to pace up and down or leave their home for long walks. This is a phase that doesn't usually continue for long.

The reasons why someone with a dementia walks or paces may not be obvious, but they may leave the house intending to go to the shops or visit a friend and then simply forget where they're going. They may be bored or uncomfortable sitting at home and want to use up some energy, or they may simply be confused about what they should be doing and where they should be.

If you notice them leaving, you might want to accompany them to guide them and make sure they don't end up being distressed.

Don't be afraid of talking to local shopkeepers and neighbours you trust to let them know about the person's dementia. Give them a contact number to call if they're concerned about the person's behaviour. If you're lucky, you may find that your area is part of a 'dementia-friendly community'.

Tracking devices and alarm systems (telecare) won't solve all your worries about someone with a dementia, but may give you some peace of mind.

Distressed behaviour

Distressed behaviour is a known symptom of dementia. This can present as aggression and can be particularly scary and upsetting when it's out of character. Seeing a loved one's personality change is worrying and may be a far more upsetting effect of dementia than memory loss.

The most common form of distressed behaviour is shouting, screaming or using offensive language, including continually calling out for someone, shouting the same word or repetitive screaming.

There are many causes of distressed behaviour in dementia, including:

- fear or embarrassment
- frustration with a situation
- depression
- no other way to express themselves
- loss of judgement
- loss of inhibitions and self-control.

It's worth keeping a note of anything that has triggered someone's distressed behaviour. This may involve some trial and error, but if you can identify these triggers, you may be able to avoid them.

During an episode of distress, try not to make the situation worse by arguing or adopting an aggressive pose as this may increase distress. It may help to count to 10 or remove yourself from the situation by leaving the room. One way to stay calm is to remember that even if the aggression seems personal or intentional, it's because of the distress.

When the person has calmed down, try to act normally with them. They may forget the incident quickly, or may feel awkward. Acting normally can help you both move forward.



Sometimes there are simple solutions to the distress – for example, a night light can make someone feel less anxious during the night, making them less likely to call out.

Becoming suspicious of others

Dementia can make some people become suspicious. This can be due to memory loss, lack of recognition of familiar faces, or general confusion caused by the effects of the condition on the brain.

The person you care for may accuse you or their friends and neighbours of taking their possessions. They may believe that everyone is out to get them. If they lose items, they may panic and become convinced that they have been burgled. Their behaviour may seem delusional and paranoid, but as their carer, try to remember that the way they feel is very real.

Listen to their worries, calm them down and, if you're sure their suspicions are unfounded, try to change the subject.

Drug treatment for dementia-related behaviour

In extreme circumstances – for example, if the person's behaviour is harmful to themselves or others, and all methods of calming them have been tried – a doctor may prescribe medication.

If you want information about drugs to help manage behavioural symptoms of dementia, or if you're concerned about the side effects of medication, speak to the person's GP.

Communicating with people with a dementia

Dementia is a progressive illness that, over time, will affect a person's ability to remember and understand basic everyday facts, such as names, dates and places.

Dementia will gradually affect the way a person communicates. Their ability to present rational ideas and reason clearly will change.

If you are looking after a person with a dementia, you may find that as the illness progresses, you'll have to start discussions to get the person to make conversation. This is common. Their ability to process information gets progressively weaker and their responses can become delayed.

Encouraging someone with a dementia to communicate

Try to start conversations with the person you're looking after, especially if you notice that they're starting fewer conversations themselves. Ways to encourage communication include:

- speaking clearly and slowly, using short sentences;
- making eye contact with the person when they're talking, asking questions or starting conversations;
- giving them time to respond, because they may feel pressured if you try to rush their answers;
- encouraging them to join in conversations with others, where possible;
- letting them speak for themselves during discussions about their welfare or health issues;
- trying not to patronise them or ridicule what they say;

- acknowledging what they say, even if they don't answer your question, or what they say seems out of context – show that you've heard them and encourage them to say more about their answer;

- giving them simple choices – avoid creating complicated choices for them;

- using other ways to communicate – such as rephrasing questions because they can't answer in the way they used to.



Communicating through body language and physical contact

Communication isn't just talking. Gestures, movement and facial expressions can all convey meaning or help you get a message across. Body language and physical contact become significant when speech is difficult for a person with a dementia.

When someone has difficulty speaking or understanding, communicating can be made easier by:

- being patient and remaining calm, which can help the person communicate more easily;
- keeping your tone of voice positive and friendly, where possible;
- talking to them at a respectful distance – if the person is sitting down, it can be a good idea to be on the same level or lower than them to help them feel more in control of the conversation;

- patting or holding the person's hand while talking to them can reassure them and make you feel closer – watch their body language and listen to what they say to see whether they're comfortable with you doing this.

It's important that you encourage the person to communicate what they want, however they can. Remember, we all find it frustrating when we can't communicate effectively, or are misunderstood.

Listening and understanding

Communication is a two-way process. As a carer of someone with a dementia, you will probably have to learn to 'listen' more carefully.

You may need to be more aware of non-verbal messages, such as facial expressions and body language. You may have to use more physical contact, such as reassuring pats on the arm, or smile as well as speaking.

When communicating with someone with a dementia, 'active listening' skills can help. These include:

- using eye contact to look at the person, and encouraging them to look at you when either of you are talking;
- trying not to interrupt them, even if you think you know what they're saying;
- stopping what you're doing so you can give the person your full attention while they speak;
- minimising distractions that may get in the way of communication, such as the television or radio playing too loudly, but always checking if it's okay to do so;
- repeating what you heard back to the person and asking if it's accurate, or asking them to repeat what they said;
- 'listening' in a different way – shaking your head, turning away or murmuring are alternative ways of saying no or expressing disapproval.

Treatment and support

Dementia cannot be cured and will gradually cause more severe problems.

Some types of memory loss are caused by vitamin and thyroid hormone deficiencies, which can be treated with supplements.

Other causes of memory loss can be treated surgically – for example, some brain tumours, excess fluid on the brain (hydrocephalus) or head injury.

Dementia causes degeneration of nerve and brain tissue, but you can take action to prevent further damage. It's possible to do this by reducing dementia risk factors, such as managing high blood pressure, high cholesterol and type 1 diabetes, and stopping smoking.

Although dementia currently cannot be cured, some types of medicine may prevent symptoms getting worse for a period of time. These medicines are usually given to people in the early and middle stages of the disease, to try to maintain or improve their independence.

It is fairly common for people with a dementia to have depression. If you have a dementia and depression, your GP may consider prescribing an antidepressant medication, or get you an appointment with a psychiatrist who specialises in working with older people.

Perhaps the most important type of treatment for anyone with a dementia is the care and support they receive from family, friends and healthcare professionals.

If you or a loved one have been diagnosed with a dementia, you should start planning the future care that will be required.

Discuss the options, such as Power of Attorney, with the people concerned –

your family, your GP and social services. The Alzheimer's Society has offices across Northern Ireland and provides a wide range of support to all those affected by a dementia.

Finally, there are things you or your loved one can do to maintain memory, independence and function when you have dementia.

Medicines to treat a dementia

A number of medications have been shown to be effective in treating mild, moderate and severe dementia. Depending on the particular type of dementia, the severity of the condition, or any other issues observed by the doctor, you may be prescribed medications. However, not everyone will benefit from these drugs.

Antipsychotics

Antipsychotics are medicines sometimes used to treat people whose behaviour is distressing to themselves and others – for example, if they tend to become aggressive or agitated. They are generally only considered when behavioural intervention has been unsuccessful. They are normally used for a short period of time and with caution, because they can increase the risk of cardiovascular problems, cause drowsiness and tend to make other symptoms of a dementia worse.

There is some evidence that antipsychotics can cause a range of serious side effects for people who have dementia with Lewy bodies. These include:

- rigidity;
- immobility;
- inability to communicate.

In most cases, antipsychotics are only used when there are severe symptoms of distressed behaviour that are challenging to understand and pose harm. Before being given antipsychotic drugs, the benefits and risks of treatment should be fully discussed between health and care professionals, family carers and, if possible, the person being prescribed the drugs.

If antipsychotics are used, they will be prescribed at the lowest possible dose and for the shortest possible time. The health of anyone taking antipsychotics needs to be carefully monitored.

Antidepressants

Depression is an issue for many people with a dementia, perhaps linked to frustrations caused by the condition.

Depression can sometimes make the memory of a person with a dementia worse. Antidepressants may be prescribed.

Psychological treatments for dementia

Psychological treatments do not slow down the progression of a dementia, but they can help with the symptoms.

Cognitive stimulation and reality orientation therapy

Cognitive stimulation involves taking part in activities and exercises designed to improve memory, problem-solving skills and language ability.

Reality orientation therapy reduces feelings of mental disorientation, memory loss and confusion, while improving self-esteem.

Evidence suggests that cognitive stimulation can improve thinking and memory skills in people with a dementia. It is currently the only psychological treatment directly recommended by the National Institute for Health and Care Excellence (NICE) to help people with a mild or moderate dementia.

Reality orientation may also be beneficial in some cases, but the benefits can be small and are often only apparent with continued effort.

Validation therapy

Validation therapy focuses on a dementia from an emotional, rather than factual, perspective. It is based on the principle that even the most confused behaviour has some meaning for the person.

For example, if someone with a dementia becomes agitated at a certain

point every day because they believe their mother is going to come and pick them up, telling them that their mother is no longer alive could cause them to become more agitated and distressed.

With validation therapy, the response to this situation might involve not correcting the person and accepting their concerns, but talking to them about the issue and gradually steering the conversation in another direction. In theory, this should reduce their distress, while acknowledging that their thoughts and feelings have meaning for them.

However, while validation therapy may sometimes be used as part of the treatment of someone with a dementia, there is not enough evidence on the effectiveness of this approach to be certain whether it is beneficial.

Behavioural intervention

Behavioural intervention offers understanding and non-pharmacological management of behaviours that carers of people with a dementia find challenging to understand. The goal is to find reasons for the behaviour. The behaviour is often a sign of the stress and distress the person with dementia experiences as they try to cope with the daily challenges of living with their illness. To fully understand the meaning of a person's behaviour, it is important to try to understand the behaviour from the perspective of that person. Could the person be experiencing pain or discomfort? Do they have access to a range of activities they enjoy? Is the environment too warm or too noisy? Making simple changes to the environment or engaging in activity can reduce distress.

For example, a person with a dementia may have a history of wandering out of their home or care centre because they feel restless. Therefore, encouraging them to take part in regular physical exercise may help decrease their restlessness.

Behavioural intervention can be used to treat many of the behavioural problems associated with dementia, such as depression, aggression and delusional thinking. Behavioural intervention is often given by a trained friend or relative (usually the main family carer), or by an employed carer, but is supervised by a healthcare professional.

Planning for the future

Enduring power of attorney

There may come a time when your dementia makes it more difficult to manage your property and financial affairs. You may need someone to do this for you. You can formally appoint a friend, relative or professional to hold a power of attorney that will allow them to act on your behalf.

A power of attorney is a legal document giving someone else the authority to take actions or make decisions on your behalf. It enables you to choose a person or people (called an attorney) to deal with your property and affairs. A power of attorney ceases when you become mentally incapable of managing your affairs, but an enduring power of attorney will continue.

You can cancel or amend the enduring power of attorney at any time while you are mentally capable. For example if the attorney you have chosen dies or becomes incapable or no longer wishes to act on your behalf you will need to appoint a new attorney.

Although this can seem like a daunting process, there is help and support to make this as easy as possible. It is vital a person with a dementia is empowered to plan for their future as soon as possible and having a conversation around enduring power of attorney is a key part of this planning.

For further information contact:

The Office of Care and Protection
Room 2.2A, Second Floor
Royal Courts of Justice
Chichester Street
Belfast
BT1 3JF
Telephone: 028 9072 5953

Financial matters

There are a wide range of benefits and financial support available if you have a dementia or support someone with a dementia. It is vital you receive all the help and support available to you to help with the journey of dementia. Please speak to your key worker about the range of benefits and support available.

Driving and dementia

Some people with a dementia prefer to give up driving because they find it stressful, but others continue driving for some time. To continue driving, you must inform the Driver and Vehicle Licensing Agency NI (DVLNI) that you have a dementia.

The DVLNI will ask for medical reports and possibly a special driving assessment to decide whether you can continue driving.

Seeking support

There is a lot of support available to all those affected by a dementia, both from the statutory sector and from the community and voluntary sector. These may include support groups, befriending, advocacy and many other forms of support to decrease social isolation. No one should have to go through this journey alone and social interaction is vital to maintaining a healthy life and living well with a dementia.

It is also very important to be as informed as possible about the journey of dementia and there is a great deal of quality information available to help with this. This can be found online, in printed formats or by talking to your GP or healthcare professional.



After a diagnosis, who can help?

- **GP** – The GP is not only involved in the diagnosis of dementia, they can also play an important role in the on-going support those affected by the condition require. The GP knows the person with a dementia's medical history and can help manage conditions that can occur alongside certain forms of dementia eg high blood pressure, high cholesterol, and depression. The GP can also refer into more specialist dementia services and give advice on how to lead a healthy lifestyle.
- **Consultant** – This can be a consultant psychiatrist, geriatrician or neurologist. Consultants may be involved in diagnosing dementia but also in the on-going assessment and support for those affected.
- **Local memory service team** – This is a team who specialise in providing a range of support services to people with a dementia and those who support them. These include assessment, diagnosis and treatment as well as information, education and support. The members of a memory service team are multidisciplinary and can include a specialist memory nurse, social workers, occupational therapists and an independent nurse prescriber.
- **Other healthcare professionals** – Speech and language therapists, clinical psychologists, dieticians and physiotherapists can provide vital support for the person with a dementia in helping them communicate and lead a full and independent life for as long as possible. They also provide help and support as the condition progresses to the later stages.
- **Dementia Navigators** – These are professionals within each Health and Social Care Trust whose role it is to provide information and support to those affected by a dementia. They will be with the person from the beginning of their journey and provide support throughout the whole experience. They will provide support either in a face to face capacity or over the telephone and will be a vital link person for all those affected by a dementia in the region.

- **Community and voluntary organisations** – These organisations can provide great support to all those affected by a dementia. They can provide information in various ways and also run information sessions. They provide some excellent peer support services for people with a dementia and their carers, and can be a strong voice for all those affected by a dementia in the region.
- **Wider healthcare** – It is important that when someone gets a diagnosis of a dementia, they do not neglect other aspects of their health as this can lead to the symptoms of dementia becoming more pronounced. For this reason, it is important to look at eye care, hearing loss, oral hygiene and care and many other factors which can help a person lead a full and healthy life.





Public Health Agency
12-22 Linenhall Street, Belfast BT2 8BS.
Tel: 0300 555 0114 (local rate).
www.publichealth.hscni.net

