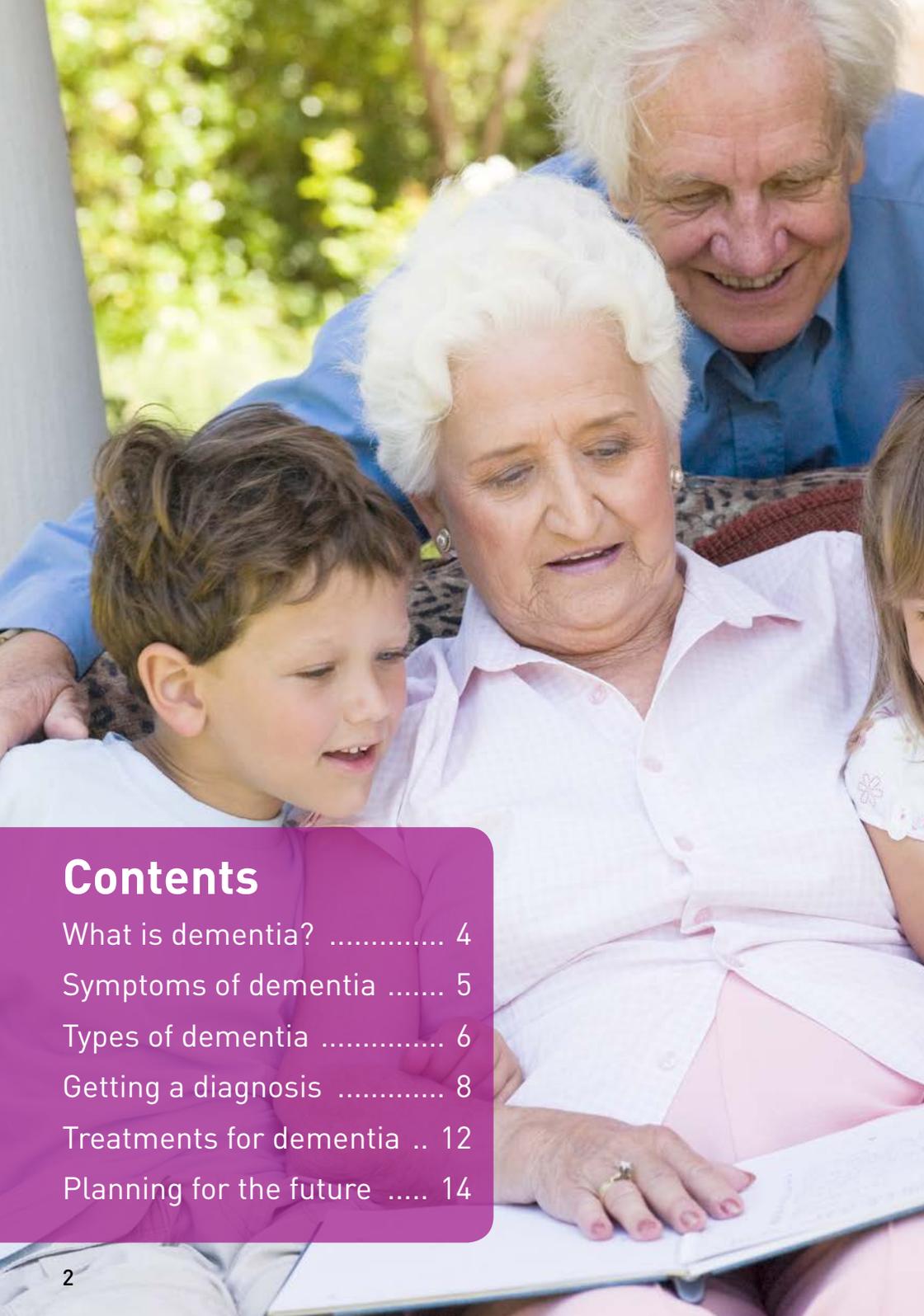


Are you worried about dementia?





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If you're becoming increasingly forgetful, particularly if you're over the age of 65, it may be a good idea to talk to your GP about the early signs of dementia.

It's normal for your memory to be affected by age, stress, tiredness, or certain illnesses and medications. This can be annoying if it happens occasionally, but if it's affecting your daily life or is worrying you or someone you know, you should talk to your GP.

If you're forgetful, it doesn't mean you have a dementia. Memory problems can also be caused by depression, stress, drug side effects, or other health problems. It can be just as important to rule out these other problems or find ways to treat them. Your GP will be able to run through some simple checks and either reassure you, give you a diagnosis, or refer you to a specialist for further tests.

This booklet describes the common symptoms of a dementia and how to get a diagnosis. It also describes the support available after a diagnosis.

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.

There is no certain way to prevent all types of dementia. However, a healthy lifestyle can help lower your risk of developing a dementia when you're older. It can also prevent cardiovascular diseases, such as strokes and heart attacks.

To reduce your risk of developing a dementia and other serious health conditions, it's recommended that you:

- eat a healthy diet;
- maintain a healthy weight;
- exercise regularly;
- don't drink too much alcohol;
- stop smoking (if you smoke);
- make sure to keep your blood pressure at a healthy level.

You can find out more about the risk factors for dementia at www.nidirect.gov.uk/dementia



Symptoms of dementia

Early symptoms of dementia are often mild and may get worse very gradually. This means you might not notice if you have them. Family and friends may not notice them or take them seriously for some time.

With dementia, the brain becomes more damaged and works less well over time. The symptoms of a dementia tend to change and become more severe.

For this reason, it's important to talk to your GP sooner rather than later if you're worried about memory problems.

The speed at which symptoms get worse, and the way symptoms develop, depends on what's causing the dementia, as well as overall health. This means the symptoms and experience of a dementia can vary greatly from person to person.

People with a dementia can become apathetic or uninterested in their usual activities and have problems controlling their emotions. They may also find social situations challenging and lose interest in socialising. Aspects of their personality may change.

A person with a dementia may lose empathy (understanding and compassion), may see or hear things that other people do not (hallucinations), or may make false claims or statements.

As dementia affects a person's mental abilities, they may find planning and organising difficult. Maintaining their independence may also become a problem. A person with a dementia will therefore usually need help from friends or relatives, including help with decision-making.

Types of dementia

Dementia is not a disease, but a collection of symptoms that result from damage to the brain. These symptoms can be caused by a number of conditions.

Some people may also have more than one condition – for example, they may have Alzheimer’s disease and vascular dementia at the same time. Although dementia has many symptoms that are similar whatever the cause, the different forms of dementia do have some particular symptoms.

Alzheimer’s disease

The most common cause of dementia is Alzheimer’s disease. Common symptoms of Alzheimer’s disease and other forms of dementia include:

- memory loss – especially for recent events, such as forgetting messages, forgetting routes or names, and asking questions repetitively;
- increasing difficulties with tasks and activities that require organisation and planning;
- becoming confused in unfamiliar environments;
- difficulty finding the right words;
- difficulty with numbers and/or handling money in shops;
- changes in personality and mood;
- depression.

Vascular dementia

The symptoms of vascular dementia can sometimes develop suddenly and quickly get worse, although they can also develop gradually over many months or years.

People with vascular dementia may also experience stroke-like symptoms, including muscle weakness or paralysis on one side of their body.

Dementia with Lewy bodies

Dementia with Lewy bodies has many of the symptoms of Alzheimer's disease and people with the condition typically also experience:

- periods of being alert or drowsy, or fluctuating levels of confusion;
- visual hallucinations;
- becoming slower in their physical movements.

Frontotemporal dementia

Early symptoms of frontotemporal dementia typically include changes in emotion, personality and behaviour. For example, someone with this type of dementia may become less sensitive to other people's emotions, perhaps making them seem cold and unfeeling.

They may also lose some of their inhibitions, leading to behaviour that is out of character, such as making tactless or inappropriate comments.

Some people with frontotemporal dementia also have language problems. This may include not speaking, speaking less than usual or having problems finding the right words.

Getting a diagnosis

Dementia is one of the health conditions that frightens people the most.

You may find it hard to accept that memory problems are affecting your life. If you're concerned about memory or other problems associated with a dementia, it's normal to be reluctant to seek help and face such a diagnosis. However, there are potential benefits to getting medical advice.

A timely diagnosis can help you get the right treatments and find the best sources of support. It can also help you make decisions about the future.

What to expect when you see your GP about dementia

Your GP will ask about your symptoms and other aspects of your health, and give you a physical examination. The doctor will organise some blood tests and ask about any medications you are taking, as these can sometimes cause symptoms similar to dementia.

You will also be asked some questions or given some mental exercises to measure any problems with your memory or ability to think clearly.





A dementia diagnosis can help uncertainty

It may not be clear why you have problems with your memory or why your behaviour has changed. These problems may be because of a dementia, or down to other reasons such as poor sleep, low mood, medications or other medical conditions. This uncertainty can be distressing for both you and your family and friends.

While a diagnosis of a dementia can be difficult, an explanation of what the problem is and what can be done about it may help you feel empowered and reduce some of the worry caused by uncertainty.

Some people find it helpful to discuss with doctors and nurses how the dementia may affect them or their loved one in the future. There is advice available on how to stay independent with dementia and live well with a dementia.

Referral to a dementia specialist

Dementia can be difficult to diagnose, especially if your symptoms are mild. If your GP is unsure about your diagnosis, they will refer you to a specialist memory service such as a psychiatrist with experience of treating dementia, an elderly care physician or a neurologist (an expert in treating conditions that affect the brain and nervous system).

The specialist may be based in a memory clinic alongside other professionals who are experts in diagnosing, caring for and advising people with a dementia and their families.

It's important to make good use of your consultation with the specialist. Write down questions you want to ask and make a note of any medical terms the doctor might use. Ask if you can come back if you think of any more questions. Taking the opportunity to go back can be very helpful.

The specialist may want to organise further tests, which may include brain scans such as a computerised tomography (CT) scan, or preferably a magnetic resonance imaging (MRI) scan.

If they are still not certain about the diagnosis, you may need to have further, more complex tests.

Getting your dementia diagnosis

Once you've had the necessary tests, your doctor should ask if you want to know your diagnosis.

They should explain what having a dementia might mean for you, and should give you time to talk more about the condition and ask any questions you may have.

Unless you decide otherwise, your doctor or a member of their team should discuss with you and your family:

- the type of dementia you have, or if it is not clear, what the plan to investigate further will entail – sometimes, despite investigations, a diagnosis may not be clear, in which case the doctors will review you again after a period of time to reassess you;
- details about symptoms and how the illness might develop;
- appropriate treatments you might be offered;
- care and support services in your area;



- support groups and voluntary organisations for people with a dementia and their families and carers;
- advocacy services;
- where you can find financial and legal advice.

You should also be given written information about dementia.

Questions to ask about your dementia diagnosis

In case you can't think of any questions to ask your doctor, it may be worth asking:

- which type of dementia you have;
- what details about the tests or investigations you should have;
- how long you will have to wait until you have the tests;
- how long it will take to get the results of these tests;
- what will happen after you get the results.

Treatments for dementia

Dementia is not a single condition – it refers to difficulties with thinking and memory that may be caused by several different underlying diseases. This is one reason why not everyone with a dementia experiences the same problems.

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.

A timely diagnosis 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 be of 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 maintaining 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.

Other support if you have a dementia

Whether or not there are specific treatments for the cause of the dementia affecting you, having the right diagnosis is important for getting the right advice and support. There is a wide variety of help and information available, both for people with a dementia and their friends, relatives and carers.

Advice and support for other medical conditions

If doctors and nurses are aware that a person has a condition causing a dementia, this is also helpful when treating other medical problems. This includes taking extra time to explain things to patients in a way they can understand, setting up safer ways of taking medication (for example, pill organiser boxes that help you remember when to take tablets), and understanding and offering extra support if someone has to come into hospital as an inpatient for another reason.

Ongoing dementia assessment

Once you have been given a diagnosis, your GP should arrange to see you from time to time to check how you're getting on. Because dementia is a progressive condition, the doctor may arrange another appointment with the specialist, perhaps after six months or a year.

The GP and the specialist may also jointly prescribe medications that may be helpful in treating some of the symptoms of dementia. However, not everybody will benefit from these drugs.

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, 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 available 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 is 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 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 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 sectors. These may include support groups, befriending, advocacy, 'singing for the brain' 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 for 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. This can be found online at www.nidirect.gov.uk/dementia, in printed formats or by talking to your GP or healthcare professional.



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

