Memory Loss and Dementia

Many people become forgetful as they become older. This is common and is often not due to dementia. There are also other disorders such as depression and an underactive thyroid that can cause memory problems. Dementia is the most serious form of memory problem. It causes a loss of mental ability, and other symptoms. Dementia can be caused by various disorders which affect parts of the brain involved with thought processes. Most cases are caused by Alzheimer's disease, vascular dementia, or dementia with Lewy bodies. Symptoms of dementia develop gradually and typically become worse over a number of years. The most important part of treatment for dementia is good-quality support and care for the person with dementia and for their carers. In some cases, treatment with medicines may be helpful.

What is memory loss and what are the causes?

Everybody forgets things from time to time. In general, the things that you tend to forget most easily are the things that you feel do not matter as much. The things that you tend to remember most easily are the things that are important to you - for example, a special birthday. However, some people just seem to have a better memory than others, and some people are more forgetful than others.

There are certain situations that can affect your memory and make you become more forgetful than you normally are. They can include the following.

Poor concentration

If your concentration is poor then you do not notice things as much, and do not retain things as much as you would normally. Poor concentration can be a result of simply being bored or tired. However, it can also be a symptom of depression and anxiety.

Depression

As well as poor concentration, some people with depression also have slowed thinking. This can cause memory problems until the depression clears. Do tell a doctor if you think that you are depressed, as treatment often works well. Other symptoms of depression include: a low mood for most of the time; loss of enjoyment and interest in life; abnormal sadness; weepiness; feelings of guilt or being useless; poor motivation; sleeping problems; tiredness; difficulty with affection; poor appetite; being irritable or restless.

Physical illness

If you feel ill, this can affect concentration and memory. Certain illnesses can directly affect the way your brain works. For example, an underactive thyroid can slow down your body's functions, including your brain, and can make you more forgetful. Infections such as a chest infection or a urine infection can also cause sudden confusion and memory problems, particularly in older people.

Medicines

Certain medicines can cause confusion and memory problems in some people. For example, some sedative medicines, some painkilling medicines, some medicines that are used to treat Parkinson's disease, or steroid medicines. Also, if you are taking lots of different medicines, this can increase the risk of them interacting with each other, causing problems, including confusion and memory problems.

Age

As everyone gets older, it often becomes harder to remember things. This is called age-associated memory impairment. Many people over the age of 60 have this common problem, and it is not dementia. For example, it tends to be harder to learn new skills the older you become, or you may more easily forget the names of people you have recently met. It is thought that the more you use your brain when you are older, the more it may counter the development of this age-related decline in memory function. So, doing things such as reading regularly, quizzes, crosswords, memorizing plays or poetry, learning new skills, etc, may help to keep your memory in good shape.

Dementia

Dementia is the most serious form of memory problem. The rest of this leaflet is just about dementia.

What is dementia?

Dementia is a condition of the brain which causes a gradual loss of mental ability, including problems with memory, understanding, judgement, thinking and language. In addition, other problems commonly develop, such as changes in personality and changes in the way a person interacts with others in social situations. As dementia progresses, a person's ability to look after themself from day to day may also become affected. There are various causes of dementia.

What are the different causes of dementia?

Dementia can be caused by various diseases or disorders which affect the parts of the brain involved with thought processes. However, most cases are caused by Alzheimer's disease, vascular dementia, or dementia with Lewy bodies (DLB). All of these types of dementia cause similar symptoms but some features may point to a particular cause. However, it may not be possible to say what is causing the dementia in every case.

Alzheimer's disease

This is the most common type of dementia, causing about half of all cases. It is named after the doctor who first described it. In Alzheimer's disease the brain shrinks (atrophies) and the numbers of nerve fibres in the brain gradually reduce. The amount of some brain chemicals (neurotransmitters) is also reduced - in particular, one called acetylcholine. These chemicals help to send messages between brain cells. Tiny deposits called plaques also form throughout the brain. It is not known why these changes in the brain occur, or exactly how they cause dementia. Alzheimer's disease gradually progresses (worsens) over time as the brain becomes more and more affected.

Vascular (blood vessel) dementia

This causes about a quarter of all cases of dementia. It is due to problems with the small blood vessels in your brain. The most common type is called multi-infarct dementia. In effect, this is like having many tiny strokes, that otherwise go unrecognised, throughout the thinking part of the brain. A stroke is when a blood vessel blocks and stops the blood getting past. So, the section of brain supplied by that blood vessel is damaged or dies (an infarct occurs). After each infarct, some more brain tissue is damaged. So, a person's mental ability gradually declines. Vascular dementia can also sometimes happen after a more major stroke.

The risk of developing vascular dementia is increased by the same things that increase the risk of stroke. For example: high blood pressure, smoking, high cholesterol level, lack of exercise, etc. (See separate leaflet called *'Preventing Cardiovascular Diseases'* for more details.) However, it is now thought that these vascular risk factors may also be involved in the development of Alzheimer's disease and other types of dementia as well.

Lewy body dementia / dementia with Lewy bodies (DLB)

This causes about 15 in every 100 cases of dementia. Lewy bodies are tiny abnormal protein deposits that develop in nerve cells in the brain of people with this condition. It is not clear why the Lewy bodies develop but they interfere with the normal working of the brain.

If Lewy bodies develop in a part of the brain called the brain stem, as well as symptoms of dementia, someone may also develop symptoms similar to Parkinson's disease. For example, stiffness, slowness of movement and a shuffling walk with difficulty in starting, stopping, and in turning easily.

Mixed dementia

Some people can have a degree of two different types of dementia at the same time. For example, both Alzheimer's disease and vascular dementia, or both Alzheimer's disease and DLB. This is known as mixed dementia. However, in most cases of mixed dementia, there is usually one of the causes for dementia that is thought to be predominant. In this situation, treatment is aimed at the predominant cause of dementia.

Other causes of dementia

There are over 60 diseases which can cause dementia. Many are rare and, in many, the dementia is just part of other problems and symptoms. In most cases the dementia cannot be prevented or reversed. However, in some disorders the dementia can be prevented, or stopped from getting worse if treated. For example, some cases of dementia are caused by alcohol abuse, infections such as syphilis, or some vitamin deficiencies, all of which can be treated.

Who gets dementia?

Dementia is a common problem. Sometime after the age of 65 about 1 in 20 people in the UK will develop dementia. Over the age of 85, about 1 in 5 people are living with dementia. However, dementia is *not* a normal part of ageing. It is different to the age-associated memory impairment that is common in older people. Rarely, dementia affects younger people. Dementia is said to be early-onset (or young-onset) if it comes on before the age of 65. There are some groups of people who are known to have a higher risk of developing dementia. These include people with:

- Down's syndrome or other learning disabilities. People with Down's syndrome are more likely to develop Alzheimer's disease.
- Parkinson's disease.
- Risk factors for cardiovascular disease (angina, heart attack, stroke and peripheral vascular disease). The risk factors for cardiovascular disease (high blood pressure, smoking, high cholesterol level, lack of exercise, etc) are risk factors for *all* types of dementia, not just vascular dementia.
- Severe psychiatric problems such as schizophrenia or severe depression. It is not clear why this is the case.
- Lower intelligence. Some studies have shown that people with a lower IQ and also people who do not have very high educational achievement are more likely to develop dementia.
- A limited social support network.
- Low physical activity levels. A lack of physical activity can increase your risk of dementia. (See separate leaflet called *'Physical Activity for Health'* for more details.)

Dementia also seems to run in some families so there may be some genetic factors that can make someone more likely to develop dementia. We do know that a few of the more rare causes of dementia can be inherited (can be passed on through genes in your family).

What are the main dementia symptoms?

The symptoms of all types of dementia are similar. They can be divided into three main areas:

Loss of mental ability

Memory problems are usually the most obvious symptom in people with dementia. Forgetfulness is common. As a rule, the most recent events are the first forgotten. For example, a person with early stages of dementia might go to the shops and then cannot remember what they wanted. It is also common to misplace objects. However, events of the past are often remembered well until the dementia is severe. Many people with dementia can talk about their childhood and early life. As dementia progresses, sometimes memory loss for recent events is severe and the person may appear to be living in the past. They may think of themselves as young and not recognise their true age.

Someone with dementia may not know common facts when questioned (such as the name of the Prime Minister). They may have difficulty remembering names or finding words. They may appear to be asking questions all of the time.

Language problems can also develop. For example, someone with dementia may have difficulty understanding what is said to them or understanding written information. Problems with attention and concentration can also occur. It is common for someone with dementia not to be able to settle to anything and this can make them appear restless.

New surroundings and new people may confuse a person with dementia: they can become easily disorientated. However, in familiar places, and with old routines, they may function well. This is why some people with mild dementia cope well in their own home. Losing track of time is also a common problem in someone with dementia. For example, not knowing if it is morning or afternoon, or what day it is. A person with dementia may get lost easily.

Even clever people who develop dementia find it difficult to grasp new ideas or learn new skills. For example, how to use a new household gadget. The ability to think, calculate and problem-solve can be affected as intellect begins to fail. Difficulties with planning and decision making can develop.

Changes in mood, behaviour and personality

At first, someone with dementia may appear to be easily irritated or moody. It is often family or friends who notice this. Some people with early dementia recognise that they are failing and become depressed. However, many people with dementia are not aware that they have it. They may remain cheerful. The distress is often felt more by relatives who may find it difficult to cope.

More challenging behaviour may develop in some people over time. For example, in some cases, a person with dementia may become quite disinhibited. This means that he or she may say or do things quite out of character. This is often difficult for families and friends to cope with. Some people with dementia can also become agitated or even agressive and this may be directed towards their carers. They may become suspicious or fearful of others and, in some people, delusions (abnormal beliefs) and hallucinations (a false perception of something that is not really there) can occur. (Visual hallucinations can be a common problem in DLB.)

Mood, behaviour and personality changes may mean that someone with dementia is not able to interact with others in a social situation and they can become quite withdrawn. Sleep is often affected and pacing and restless wandering can become a problem for some.

Problems carrying out day-to-day activities

Difficulty with self-care usually develops over time. For example, without help, some people with dementia may not pay much attention to personal hygiene. They may forget to wash or change their clothes. Remembering to take medication can become an issue. The person may also have difficulty keeping up their home. Shopping, cooking and eating may become difficult. This can lead to weight loss. Driving may be dangerous and not possible for someone with dementia.

How does dementia progress?

The speed in which dementia progresses varies greatly from person to person. It can also depend on the type of dementia that someone has. Typically, symptoms of dementia tend to develop slowly, often over several years. In the early stages of the disease, many people with mild dementia cope with just a small amount of support and care. As the disease progresses more care is usually needed.

In the later stages of dementia, speech may be lost and severe physical problems may develop, including problems with mobility, incontinence, and general frailty. This can make people more susceptible to other health problems such as infections. Often, people with dementia die from another health problem such as a severe chest infection. So, the dementia isn't the cause of their death but has contributed to it.

Some people can live for many years after dementia has been diagnosed. However, a recent study showed that if someone is diagnosed with dementia between the ages of 60-69, on average it takes just under seven years to go from being diagnosed with dementia, to being severely affected, and ultimately to dying due to frailty of body and mind.

How is dementia diagnosed?

Because the symptoms of dementia tend to develop slowly, often over several years, they may be difficult to recognise at first. This can make dementia difficult to diagnose in some people. In the beginning, symptoms are often put down to other causes. There may also be a degree of protection by friends, carers and relatives who help the person to look after themself and, by doing so, cover up the person's inability.

Saying that, commonly, it is not the person with the symptoms but rather their relatives, carers or friends who have concerns that the person may have dementia. They may be concerned about the person's memory or behaviour. However, people with a high intellect or a demanding job, may notice themselves that their mental ability is starting to fail.

Visit your doctor

The first step if you are concerned that you may be developing dementia is to see your doctor. Or, if you are worried that someone close to you may have dementia, you should encourage them to see their doctor. They may agree for you to see their doctor with them.

Your doctor may suggest some special tests to look at your memory and mental ability, to see whether dementia is likely or not. This does not take long and is usually a series of questions or other exercises that your doctor asks you to complete.

Your doctor may also suggest some routine tests to make sure that there are no other obvious causes for your symptoms. For example, blood tests to look for infection, vitamin deficiencies, an underactive thyroid gland, etc. If infection is suspected, they may suggest a urine test, a chest X-ray or other investigations. They may also ask questions to make sure that your symptoms are not due to, for example, depression, any medicines that you may be taking, or excess alcohol intake.

Referral to a specialist

Referral for the opinion of a specialist is usually needed to confirm the diagnosis of dementia. This is usually a specialist in the care of elderly people, a neurologist, or a psychiatrist specialised in looking after older people. The specialist may be able to determine the likely cause of dementia and decide if any specific treatment may be helpful (see below). To help with this, they may suggest further investigations such as an MRI scan of the brain.

Other more sophisticated tests may be done if an unusual cause of dementia is suspected.

New research

Research is underway to try to find ways of diagnosing dementia earlier and more easily, as well as to try to predict who may develop it. In particular, researchers made a breakthrough recently that could help diagnose Alzheimer's disease. They identified proteins called biomarkers that seem to be present in the cerebrospinal fluid (the fluid that bathes the brain) in people who have Alzheimer's disease or who may go on to develop Alzheimer's disease. This promising study gives hope but more research is needed in this area. More recently, other researchers have been looking into certain proteins that can be detected in the blood, which they think may help to determine a more accurate and an earlier diagnosis of Alzheimer's disease. Again, this research shows good promise but further work is needed.

Can medication help people with dementia?

There is no cure for dementia and no medicine that will reverse dementia. However, there are some medicines that may be used to help in some causes of dementia. Medication is generally used for two different reasons. Firstly, as treatment to help with symptoms that affect thinking and memory (cognitive symptoms). Secondly, as treatment to help with symptoms that affect mood and how someone behaves (non-cognitive symptoms).

Acetylcholinesterase inhibitors

These include donepezil, rivastigmine and galantamine. They work by increasing the level of acetylcholine. This is a chemical in the brain that is low in people with Alzheimer's disease. These medicines are not a cure for Alzheimer's disease. However, they may help to treat *some* of the symptoms affecting thinking and memory in about half of people with Alzheimer's disease.

Previously, the National Institute for Health and Clinical Excellence (NICE) recommended that these medicines should only be considered for people with moderate Alzheimer's disease. This was quite controversial, as many people felt that they should also be available to those with mild Alzheimer's disease. However, NICE reviewed their guidance on the use of these medicines in March 2011. NICE now recommends that donepezil, galantamine and rivastigmine can be considered as treatment options for people with mild or moderate Alzheimer's disease, providing that:

- The medicine is started by a specialist in the care of people with dementia.
- A person receiving treatment has regular reviews and assessments of their condition. (Reviews are usually carried out by a specialist team. Carers' views on the person's condition should also be asked before the medicine is started and should be considered during the reviews.)
- The medicine is only continued for as long as it is thought to be having a worthwhile effect on a person's symptoms.

Common side-effects of these medicines may include feeling sick, muscle cramps, tiredness, headache and diarrhoea. Your doctor should be able to give you more details about possible side-effects.

The medicine rivastigmine is also licensed to be used in people with mild-to-moderately severe dementia who also have Parkinson's disease. So, doctors may suggest this medicine for this group of people. Also, an acetylcholinesterase inhibitor medicine may sometimes be suggested for people with DLB who have problems with challenging or disruptive behaviour (non-cognitive symptoms).

Memantine

This medicine is also licensed for the treatment of Alzheimer's disease in some people. It works by reducing the amount of a brain chemical called glutamate. It is thought that this may help to slow down the damage to brain cells affected by Alzheimer's disease. Like the medicines above, this is not a cure. Some research studies have shown that it seems to slow down the progression of the symptoms in *some* cases.

NICE has also (March 2011) reviewed its guidance about the use of memantine and recommends that it can be considered as a treatment option for:

- People who have moderate Alzheimer's disease and who for some reason cannot take, or are intolerant to, the acetylcholinesterase inhibitor medicines.
- People who have severe Alzheimer's disease.

Other medication

- **An antidepressant** may be advised if depression is suspected. Depression is common in people with dementia and may be overlooked.
- **Aspirin** and other medicines to treat the risk factors for stroke and heart disease may be appropriate for some people - especially those with vascular dementia.
- **Sleeping tablets** are sometimes needed if difficulty sleeping is a persistent problem.
- **A tranquilliser or an antipsychotic medicine** is sometimes prescribed as a last resort for people with dementia who become easily agitated.

There are several other medicines which have been suggested for the treatment of Alzheimer's disease. These include gingko biloba (a herbal medicine), non-steroidal anti-inflammatory drugs (NSAIDs), vitamin E, oestrogens and statins. However, there is currently not enough evidence from research trials to recommend any of these for the treatment or prevention of dementia. In particular, until recently, it was popular to take gingko biloba as a preventative treatment. Large research trials suggest that gingko biloba has little or no effect on preventing dementia but it may be helpful in improving memory for specific tasks such as remembering appointments.

Research continues and new medicines are being developed to help with dementia, which show some promise.

Support and care is the most important part of treatment

When someone is diagnosed with dementia, a full assessment may be suggested to look at their practical skills, their ability to look after themself, their safety in their home, etc. This usually involves assessment by a number of different healthcare professionals (see below). An individual care plan may be drawn up that outlines the person's specific needs. The aim is to maintain the independence of someone with dementia as much as possible and for as long as possible.

Most people with dementia are cared for in the community. Often, the main carer is a family member. It is important that carers get the full support and advice which is locally available. Support and advice may be needed from one or more of the following healthcare and allied professionals, depending on the severity of the dementia and the individual circumstances:

- District nurses can advise on day-to-day nursing care.
- Occupational therapists can advise on changes to the physical environment, which may help a person with dementia. For example, handrails and grab bars, labelling of objects, removing items that are not needed in the home.
- Physiotherapists can help. For example, with exercises to help maintain mobility.
- Community psychiatric nurses can advise on caring for people with mental illness. Sometimes a specialist assessment by a psychiatrist may be needed.
- Social Services can advise on local facilities such as daycare centres, benefits, help with care in the home, sitting services, respite care, etc.
- Voluntary organisations can be a good source of advice. If you care for a person with dementia, it is well worth getting information about the help that is available in your local area. In most areas of the UK there are organisations that provide support and advice for carers of people with dementia. Your local library or citizens advice bureau will often have contact details. Some organisations are also listed at the end of this leaflet.

The level of care and support needed often changes over time. For example, some people with mild dementia can cope well in their own home which is very familiar to them. Some may live with a family member who does most of the caring. If things become worse, a place in a residential or nursing home may be best. The situation can be reviewed from time to time to make sure the appropriate levels of care and support are provided.

Many carers struggle on beyond the point that is appropriate. If you are a carer, you can ask a GP or district nurse to assess a person with dementia if you feel that you need a greater level of support. The Carer's Association (contact information listed below) may also be able to provide support and advice. For example, information about respite/short-break services for carers.

Other possible treatments

There are some other treatments and things that may be helpful for some people with dementia, particularly in certain situations. These include the following.

Measures to help simplify the daily routine and enhance memory may help some people. For example, planning out and writing down a daily routine. This may include writing reminders to do certain things such as putting the rubbish out, locking the door at night-time, etc. Making sure that clothing, keys, glasses or other things that are used often are put in prominent places where they can be found easily may also be helpful. Labelling of commonly used objects may be another useful tool. An occupational therapist may be able to advise.

Reality orientation is thought to help in some cases. This involves giving regular information to people with dementia about times, places, or people to keep them orientated. It may range from simple things such as having a board in a prominent place, giving details of the day, date, season, etc, to staff in a residential home reorientating a person with dementia at each contact.

Cognitive stimulation (stimulating the brain) may help to improve memory, language and problem-solving ability. For example, by recreational activities, problem-solving activities, and talking to the person with dementia. In addition, recreational activities may enhance quality of life and well-being.

Regular physical activity, if possible, such as walking, dancing, etc, may help to slow down the decline in mobility that is common in people with dementia. It may also help if depression is a problem.

Reminiscence therapy may help in some cases. This involves encouraging people to talk about the past so that past experiences are brought into their current thoughts. It relies on long-term memory which is often quite good in people with mild-to-moderate dementia.

Cognitive behavioural therapy is sometimes tried to help treat depression that is quite common in people with dementia.

Behavioural therapy may also be used to treat any problems related to behaviour that someone with dementia may have. This type of therapy looks for possible reasons for certain behaviours. For example, someone who wanders a lot may in fact be doing this because they are feeling quite restless. In this situation, taking part in regular physical activity may help.

Animal-assisted therapy may sometimes be suggested to help people with dementia who have challenging behaviour such as agitation or aggression. For example, allowing the person to spend time with and interact with a trained dog.

Sensory stimulation - for example, using music, lights, sounds, smells, massage and aromatherapy to stimulate the brain. This may also be helpful for some people with dementia - for example, to improve their mood or feelings of restlessness.

Driving and dementia

Vehicle drivers who have been diagnosed with dementia are legally required to inform the Driver and Vehicle Licensing Agency (DVLA). They may be able to continue driving a car or a motorcycle safely for some time. But they may be asked to have a driving test and/or their doctor may be asked to complete a medical report for the DVLA. If someone is able to continue to drive, this will usually be reviewed on a yearly basis. Someone who has been diagnosed with dementia will not be able to continue to drive a bus (or other vehicle that carries passengers) or a lorry or large goods vehicle.

Can dementia be prevented?

At present, there are no specific medicines or treatments that are definitely known to reduce your chance of developing dementia. However, some things do show some promise.

As mentioned above, having risk factors for cardiovascular disease (including smoking, raised cholesterol levels, drinking too much alcohol, not doing enough physical activity, being overweight, having diabetes or high blood pressure) can increase your risk of developing all types of dementia. Therefore, it would seem likely that doing something to modify these risk factors may reduce your risk of developing dementia.

Keeping your brain active may also help to reduce your risk of developing dementia. So, for example, consider reading books, learning a foreign language, playing a musical instrument, taking up a new hobby, etc.

A study published in 2010 showed that a group of medicines used to treat blood pressure, called angiotensin receptor blockers, may help to protect against dementia. The study looked at more than 800,000 people, mostly men, who were treated for high blood pressure over a four-year period. It found that those who took angiotensin receptor blockers were less likely to develop dementia during that time when compared with people taking other medicines to treat high blood pressure. People in the same study who were taking angiotensin receptor blockers plus another medicine from a group known as angiotensin-converting enzyme (ACE) inhibitors, had an even lower risk of developing dementia.

In the same study, those taking angiotensin receptor blockers who had already been diagnosed with dementia were less likely to need admission to a nursing home or to die prematurely during the same period. This raises the possibility that these medicines may also help to slow down the progression of dementia in those already diagnosed. It is not clear why these medicines may help to prevent or delay the progression of dementia. It is thought that they perhaps help to protect nerve cells in the brain from damage in some way. Further research is needed to clarify their role in the prevention and treatment of dementia.

Further research is ongoing to try to find other ways of preventing dementia.

Further advice, information and help

Alzheimer's Society

Devon House, 58 St Katharine's Way, London E1W 1LB
Tel (Helpline): 0845 300 0336 Web: www.alzheimers.org.uk
Also provides information on other types of dementia and not just on Alzheimer's disease.

Mental capacity and the law

Web: www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/index.htm
Information from DirectGov. Includes information such as: Making legal arrangements in case you lose mental capacity; What is a Lasting Power of Attorney? Making decisions for someone else; How to decide if a person lacks mental capacity, etc.

The Lewy Body Society

Hudson House, 8 Albany St, Edinburgh EH1 3QB Tel: 0131 473 2385 Web: www.lewybody.org

Carers UK

20 Great Dover Street, London SE1 4LX
Advice line: 0808 808 7777 Web: www.carersuk.org
Aims to help anyone who is caring for a sick, disabled, or elderly friend or relative at home.

The Princess Royal Trust for Carers

Unit 14, Bourne Court, Southend Road, Woodford Green, Essex, IG8 8HD
Tel: 0844 800 4361 Web: www.carers.org Supports a national network of centres where unpaid carers can obtain advice, information and support. Telephone the national office for details of your nearest centre.

Further reading & references

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