

Carers Information Sheet 21

Carers of People with Dementia

This Leaflet is for carers of people who have some form of 'Dementia' including Alzheimer's Disease, Lewy Bodies Dementia, Vascular Dementia, etc. It will give you some basic information about dementia and where you might get more information or practical and/or emotional support in your caring role.

What is dementia?

Dementia is a term used to describe various different brain disorders that have in common a loss of brain function that is usually progressive and eventually severe. There are over 100 different types of dementia. The most common are Alzheimer's disease, Vascular Dementia and Dementia with Lewy bodies. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding.

Dementia is an umbrella term, that is used to describe many different symptoms that occur when the brain has been damaged by different diseases and conditions.

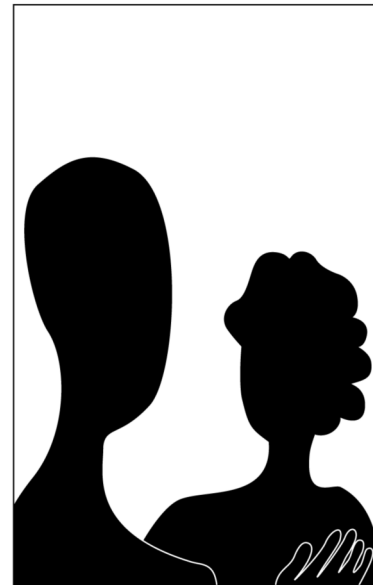
COMMON FORMS OF DEMENTIA

Alzheimer's Disease

Alzheimer's disease is the most common form of dementia, affecting around 500,000 people in the UK. It was first described by the German neurologist Alois Alzheimer. It is a physical disease affecting the brain. During the course of Alzheimer's the person's brain cells become diseased and eventually die.

People with Alzheimer's have a shortage of some important chemicals in their brain. These chemicals are involved with the transmission of messages within the brain.

Alzheimer's is a progressive disease, which means that gradually, over time, more parts of the brain are



damaged. As this happens, the symptoms become more severe.

Symptoms

People in the early stages of Alzheimer's disease may experience lapses of memory and have problems finding the right words. As the disease progresses they may:

- Become confused, and frequently forget the names of people, places, appointments and recent events.
- Experience mood swings. They may feel sad or angry. They may feel scared and frustrated by their increasing memory loss.
- Become more withdrawn due either to a loss of confidence or to communication problems.

As the disease progresses, people with Alzheimer's will need more support from those who care for them. Eventually they will need help with all their daily activities.

While there are some common symptoms of Alzheimer's disease, it is important to remember that everyone is unique. No two cases of Alzheimer's are likely to be the same. People always experience illness in their own individual way.

What causes Alzheimer's disease?

So far, no one single factor has been identified as a cause for Alzheimer's disease. It is likely that a combination of factors, including age, genetic inheritance, environmental factors, diet and overall general health, are responsible.

Age

Age is the greatest risk factor for dementia. Dementia affects one in 20 people over the age of 65 and one in five over the age of 80. However, Alzheimer's is not restricted to elderly people: there are over 18,000 people under the age of 65 with dementia in the UK.

Genetic inheritance

Many people fear that they may inherit Alzheimer's disease. Scientists are currently investigating the genetic background to Alzheimer's. We do know that there are a few families where there is a very clear inheritance of the disease from one generation to the next. This is often in families where the disease appears relatively early in life.

In the vast majority of cases, however, the effect of inheritance seems to be small. If a parent or other relative has Alzheimer's disease, your own chances of developing the disease are only a little higher than if there were no cases of Alzheimer's in the immediate family.

Environmental factors

The environmental factors that may contribute to the onset of Alzheimer's disease have yet to be identified. A few years ago, there were concerns that exposure to aluminium might cause Alzheimer's disease. However, these fears have largely been discounted.

Other factors

Because of the difference in their chromosomal

make-up, people with Down's syndrome who live into their 50s and 60s may develop Alzheimer's disease.

People who have had severe head or whiplash injuries appear to be at increased risk of developing dementia. Boxers who receive continual blows to the head are also at risk.

Research has also shown that people who smoke and those who have high blood pressure or high cholesterol levels increase their risk of developing Alzheimer's.

An early diagnosis will:

- Help you plan for the future
- Enable the person with dementia to benefit from the treatments that are now available
- Help you identify sources of advice and support.

There is no straightforward test for dementia. A diagnosis is usually made by excluding other causes. The GP or specialist will need to rule out infection, vitamin deficiency, thyroid problems, brain tumours, the side-effects of drugs and depression.

Vascular Dementia

Vascular dementia affects around a quarter of people with dementia in the UK. This information outlines some of the causes and symptoms of vascular dementia, and offers some suggestions on how to reduce the risk of developing the condition.

What causes vascular dementia?

Vascular dementia occurs when cells in the brain are deprived of oxygen. The brain is supplied with oxygen by a network of blood vessels called the vascular system. If there is a blockage in the vascular system, or if it is diseased, blood is prevented from reaching the brain. As a result, cells in the brain die, leading to the symptoms of dementia.

Stroke and vascular dementia

Stroke is one of the most common causes of vascular dementia. A stroke occurs when blood flow in the brain is blocked by a blood clot in an artery or when an artery bursts.

When this happens the brain cells supplied by that vessel are deprived of oxygen and die. This damage is irreversible.

People who have one large stroke will experience difficulties such as paralysis on one side of the body, speech and language problems, or difficulties with coordination and movement. Vascular dementia may also develop.

Multi-infarct dementia

Sometimes people may experience a series of small strokes. When these 'mini-strokes' occur they can cause light-headedness, temporary blindness and mild weakness in the arms or legs. Often the symptoms clear up quickly and do not appear to cause any long term problems. However, these mini-strokes may cause a build up of damage in the brain which can cause dementia. This type of dementia is called multi-infarct dementia.

Binswanger's disease

Binswanger's disease is a rare form of vascular dementia that is caused by damage to blood vessels deep in the brain's 'white matter'. It is partly a result of high blood pressure.

Symptoms of vascular dementia

As with other forms of dementia, people with vascular dementia will experience memory loss, difficulties in communicating and, as the disease progresses, a loss of physical abilities. However, there are some unique symptoms of vascular dementia.

- Because vascular dementia can affect distinct parts of the brain, particular abilities may remain relatively unaffected. This is unlike Alzheimer's disease, for example, where the disease affects the entire brain.
- Some people who have vascular dementia may notice that their symptoms remain steady for a while and then suddenly decline. In people with Alzheimer's disease the decline is more constant.
- People with vascular dementia may understand what is happening to them. This may make them prone to depression.

Diagnosis

It can be difficult to diagnose whether a person has Alzheimer's disease or vascular dementia. It is also possible to have both forms of dementia. New technology is making diagnosis easier. Brain imaging techniques can reveal if areas of the brain are damaged due to stroke, which indicates vascular dementia.

However, where there is no evidence of a stroke, it is quite common for a diagnosis of Alzheimer's disease to be made.

It is important to recognise that other vascular diseases could be causing the dementia. It is very important that the type of dementia is identified because the treatments for Alzheimer's disease and vascular dementia are quite different.

Treatment and prevention of vascular dementia

Unfortunately there is no way to reverse damage to the brain once it has occurred. But, depending on the severity of the damage, with the right treatment it is possible to limit or delay the severity of the decline. The important thing is to prevent further damage occurring.

You can reduce your risk of high blood pressure, stroke and vascular dementia by:

- Not smoking
- Drinking moderate amounts of alcohol
- Reducing your intake of salt and saturated fat
- Taking regular exercise
- Having a GP check your blood pressure at least once a year
- Having your blood fat levels measured by your GP.

Dementia with Lewy Bodies

Dementia with Lewy bodies (DLB) is a form of dementia that shares characteristics with both Alzheimer's and Parkinson's diseases. It may account for 10 to 15 per cent of all cases of dementia in older people.

What are Lewy bodies?

Lewy bodies (named after the doctor who first identified them in 1912) are tiny, spherical protein deposits found in nerve cells. Their presence in the

brain disrupts the brain's normal functioning, interrupting the action of important chemical messengers.

Lewy bodies are also found in the brains of people with Parkinson's disease (PD), a progressive neurological disease that affects movement. Some people who are initially diagnosed with PD later go on to develop a dementia that closely resembles DLB. Researchers have yet to understand fully why Lewy bodies occur in the brain.

DLB is a progressive disease. This means that over time the symptoms will become worse. In general, DLB progresses at about the same rate as Alzheimer's disease, typically over several years.

People with DLB will typically have some of the symptoms of Alzheimer's and Parkinson's diseases.

- People who have DLB often experience the memory loss, spatial disorientation and communication difficulties associated with Alzheimer's disease.
- They may also develop the symptoms of Parkinson's disease, including slowness, muscle stiffness, trembling of the limbs, a tendency to shuffle when walking, loss of facial expression and changes in the strength and tone of the voice.

Symptoms characteristic of Lewy Bodies

There are also symptoms that are characteristic of DLB. People with DLB may:

- Find that their abilities fluctuate daily, even hourly
- Faint, fall, or have 'funny turns'
- Experience detailed and convincing visual hallucinations, often of people or animals
- Fall asleep very easily by day and have restless, disturbed nights with confusion, nightmares and hallucinations.

Who gets Lewy Bodies?

DLB appears to affect both men and women equally. As with all forms of dementia, DLB is more prevalent in people over the age of 65. However, in certain rare cases people under 65 may develop DLB.

Diagnosing Lewy Bodies

DLB can be difficult to diagnose. People are often diagnosed as having Alzheimer's disease or vascular dementia. The diagnosis is made on the basis of the symptoms, particularly visual hallucinations, fluctuation and the presence of the stiffness and trembling of Parkinson's. While it is always important to get an accurate diagnosis of dementia, a proper diagnosis is particularly important in cases of suspected DLB since people with DLB have been shown to react badly to certain forms of medication.

Treatment

At the moment there is no cure for DLB. Recent research suggests that the cholinesterase inhibitor drugs used to treat Alzheimer's disease may also be useful in treating DLB, although they are not yet licensed for this use.

Symptoms such as hallucinations may respond to being challenged, but it can sometimes be unhelpful to try to convince the person that there is nothing there. It is sometimes better to try to provide reassurance and alternative distractions. People who are experiencing stiffness owing to Parkinsonism may benefit from anti-Parkinson's disease drugs although these can make hallucinations and confusion worse. Physiotherapy and mobility aids may also help.

When caring for someone with DLB, it is important to be as flexible as possible, bearing in mind that the symptoms of DLB will fluctuate.

Other forms of Dementia

There are a range of other far more rare forms of dementia such as Picks Disease, Korsakoff's Syndrome and AIDs related dementia. For more information on these please look at the Alzheimer's Disease Society website:

www.alzheimers.org.uk

or contact them by phone for their Fact Sheets:

Tel: **0845 300 0336**

Coping with Caring

Caring for someone with Dementia can be extremely stressful and upsetting. You may have feelings of grief and anger about the fact that you have 'lost' the person who love. It is easy to ignore your own needs when caring for someone with dementia and to forget that you matter, too. So it is important to take steps to safeguard your own health and well-being, so that you can continue to cope and retain your confidence.

You may feel guilty, even when it seems that you are doing the best you can. Such feelings, which are very common among carers, may undermine your confidence and self-esteem and make it harder for you to cope.

It is also easy to carry on without realising how tired or tense you have become. A break or holiday can help you to relax and recharge your batteries. As a carer, it is important that you have regular breaks and make time for your own needs. This may mean organising some short term care for the person with dementia.

Carers Lewisham can provide help and support to YOU as the carer, we can be a listening ear; we have regular coffee mornings and support sessions; information days about how to cope; services to give you a break from caring; opportunities to meet other carers who may be in similar situations to yourself.

See Leaflet 1 in your pack for more information.

Tel: **020 8699 8686**

Alzheimer's Disease Society Lewisham and Greenwich

Have regular meetings to give you more information about Dementia and how to cope.

Tel: **020 8290 8190**

What steps should the Carer take after diagnosis?

- It is important that the person you are caring for is helped to retain their confidence and self esteem
- Encourage your cared for person to tell friends and family their diagnosis so they can understand some of the changes likely to occur.
- It may be helpful for you both to discuss the future so that you can both be aware of each others likes and dislikes and future wishes
- Keep a record of events, help received, visits from services, changes in medication, GP visits, etc.
- Remember to ask for results of all tests so that you can keep up to date. Sometimes there may be issues of confidentiality and these need to be discussed with the GP and others providing care for your cared for person so they are aware you are the carer.
- Ensure finances are in order and that your cared for person has a will made which reflects their wishes. You may also wish to sort out an Enduring Power of Attorney. See Carers Lewisham Information Pack Leaflets No's 7, 22 and 23 for more information on all these areas.
- Contact Lewisham Social Care Services for an assessment of your looked after person's needs and have a Carers Assessment to look after YOUR needs.
Tel: **020 8314 6000**

What is challenging behaviour?

Challenging behaviour is a term used to describe certain types of problem behaviours. It is important to understand the causes of challenging behaviour in order effectively deal with the situation. Challenging behaviour may include shouting screaming, violence, pacing and wandering, biting oneself or others, throwing objects, repetitive questioning, anger and tearfulness, outbursts or disturbed sleep pattern.

Challenging behaviour may occur if the person:

- Has a urinary or chest infection which can cause delirium
- Are in pain or discomfort
- Isdehydrated through not taking in enough fluid or losing body fluids because of vomiting or diarrhoea.

People with dementia may become aggressive if they feel:

frustrated, under pressure or humiliated because they are no longer able to cope with everyday life.

feel their independence or privacy is threatened, being forced to accept help with personal functions such as washing, dressing, or going to toilet.

feel they are being judged or criticised because they have forgotten something or have made a mistake completing an every day task.

feel nervous or threatened because they do not recognise certain places or people.

feel disorientated or anxious because there is too much noise, too many people around, or there is a change in a familiar routine.

frightened by a sudden noise, sharp voice, abrupt movement or a person approaching them from behind without warning.

Finding ways to deal with an aggressive situation:

- Prevention is the best solution for aggressive behaviour.
- If an aggressive situation does arise, do not blame yourself.
- Handling the situation as calmly and effectively as possible.
- Therapeutic intervention

Non-pharmacological intervention in dementia

Non-pharmacological intervention can reduce challenging behaviour. There are 3 types of interventions: Standard therapies, Alternative therapies and Brief psychotherapies.

Standard Therapies

Include behaviour therapy, reality orientation, validation therapy.

Alternative therapies

Include art therapy, music therapy, activity therapy, complementary therapy, multisensory approaches.

Brief Psychotherapies

Include cognitive behavioural therapy and interpersonal therapy.

THERAPEUTIC INTERVENTION:

Reality Orientation (RO)

RO is one of the most widely used management strategies for dealing with people with dementia. It aims to help people with memory loss and distortion by reminding them about facts about themselves and their environment. It can be used both with individuals and with groups. This involves consistent use of orientation devices such as sign posts, notices and other memory aids.

Validation therapy (VT):

Naomi Feil, designed validation therapy to help dementia sufferers. It relies on the patient's emotions. The idea behind VT is to 'validate' or accept the values, beliefs and reality of the person suffering from dementia. The key is to 'agree with them' but to also use conversation to get them to do something else without them realizing they are actually being redirected.

Life Story Books

This is something that you and your cared for person could do together. A Life Story book is a personal record of an individual's life which can be kept with them at all times. It could be little more than a photograph album or it could be filled with drawings, certificates, newspaper cuttings, materials, letters and anything that is special or significant to the person. It can also contain important information about such things as likes and dislikes which the person may not be able to express in speech. It can be used to jog memory and as a communication tool.

The book can be added to over time. It could include

- Family Background
- Family Relationships
- Friends
- Significant events; births marriages deaths
- Belief Systems; religious, moral, political
- Hobbies, work education, holidays
- Likes and dislikes; food, music, books, TV, colours etc.
- Instructions around a person's individual needs/requirement

Don't be afraid to be creative! Put in anything that helps 'paint a picture'.

Some good reasons for compiling a Life Story

Book:

- It provides an opportunity for communication
- It helps strengthen a person's identity and self esteem
- It gives something positive and tangible for carers to be involved with
- It helps care workers to have a respectful awareness of a person's history and identity
- It helps keep memories alive

Driving

The DVLC at Swansea and the insurance company must be informed of the diagnosis. If safety is an issue then it is advisable to talk to your cared for person about giving up driving. If you meet with reluctance get help from other family members or an authority figure such as a GP.

Driving and Dementia

If someone has been diagnosed with dementia, they may be able to continue driving for some time. However, they must fulfil certain legal requirements. If the person's condition has deteriorated to the point where they are unsafe on the road, they must stop driving. Many people find this difficult to accept.

Continuing

If someone receives a diagnosis of dementia and wants to continue to drive, they must, by law inform the DVLA. Notification of the diagnosis should be sent with the person's full **name, address, date of birth and the driver number on the driving licence.**

Smoking and Drinking

Alcohol in moderation is fine. Smoking, however needs to be under strict supervision for safety reasons.

Wandering

Try to find out why someone is wandering; they may be bored, restless or looking for things that they have lost. A curtain can disguise a door and

act as a distraction. If wandering is a problem and there are concerns for their safety it may be preferable to lock the doors. However this should be done with caution and only when absolutely necessary. At all times you should ensure that doors can be easily unlocked in case of emergency. It is preferable not to lock someone with dementia in alone.

Sleep patterns

Your cared for person may have disturbed sleep patterns as they may have a need to use the toilet; slept too much during the day; went to bed too early; is uncomfortable; or wakes up frightened. A low wattage lamp by the side of the bed and gentle reassurance may help them to settle back to sleep. If this continues it may be worth talking to your GP or Older Peoples Mental Health Team about other ideas.

Clinging Behaviour

It can be difficult to manage if the person you care for won't let you out of their sight. However it is essential for YOUR health and well-being that you have time for yourself. If you don't look after yourself you could get ill and be unable to care for the person anyway. You must investigate getting a break. A sitter could come into your home to take care of your cared for person for a few hours. There may be an opportunity for your cared for person to go to a regular Day Centre. Also your cared for person could have a break in a residential care home so that you could have a proper holiday. Sometimes using these services can be difficult and carers often feel guilty, however having a break is essential for both YOU **and** your cared for person.

Accusations of theft

Sometimes this happens because the cared for person has forgotten where they have put something. Denying you have taken things can cause someone to become more agitated and distressed. It may help if you could help the person look for the things which they say have been taken. You may find that the person has 'hiding places' where they regularly 'tidy' things away.

Your cared for person is frightened someone is coming to get them or there are people in the house

They could be suffering from 'delusions'. These are imaginary ideas but are very real to the person suffering from them. They may be caused by an infection (especially a urine infection) which is making them worse, or it could mean that the dementia has progressed. Sometimes it could be something in their home. For example a man with dementia kept saying that he saw rats running around. It turned out to be the swirl patterned carpet that was upsetting him and once a plain rug was put down over the carpet the delusions stopped. Talk to your GP or contact the Older People's Mental Health Team for advice.

Sex

This is a very sensitive and private issue, with no simple solutions. There are trained people you could talk to about any sexual problems you may be experiencing. Talk to your GP or Older Peoples Mental Health Team. (See contacts)

Trips and Falls and other hazards

Look for potential hazards and take preventative action.

- Do all fires have fire guards?
- Are carpets and rugs secure?
- Are there any trailing wires?
- Are stairs and passageways uncluttered?
- Are kitchen appliances safe?

It may be possible to remove some hazards. Some will need some specialist items that can be found in DIY shops.

CONTACTS

Older Adults Team

Services: See Leaflet 3

Tel: **020 8314 8866** and ask for the Older Adults Duty Social Worker.

Older Adults Mental Health Teams

Services: Supports older people with mental health problems and their carers.

Tel: **020 8314 6000** and ask for the Older Adult Mental Health Team for your area.

Alzheimer's Society Lewisham and Greenwich

52 Deptford Broadway, SE8 4PM

Tel: **020 8290 8190**

Mental Health Foundation

www.mentalhealth.org.uk/publications/

Useful booklet about Dementia



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