

## Dementia after stroke

Dementia is a life-changing condition that affects your ability to do everyday tasks. Over 600,000 people have dementia in the UK and it affects many more people, such as family members and friends. This factsheet is aimed at everyone affected by dementia. It explains some of the different types, in particular vascular dementia which is caused by stroke, its diagnosis and treatment, and ways to access support and help.

### What is dementia?

The word, dementia, is used to describe a **group of symptoms** that occur when the **brain is damaged by specific diseases**. This damage causes a decline in a person's ability to do things. A person with dementia may have:

- memory problems
- communication difficulties
- problems understanding
- reduced ability to concentrate
- mood changes.

Dementia is a **progressive condition**, which means it gets worse over time. The way someone experiences dementia and the speed at which it progresses can vary.

### What are the different types of dementia?

There are different types of diseases and conditions that cause dementia.

**Alzheimer's disease** is the most common cause, accounting for 50 to 60 per cent of all dementia cases. It is a physical disease affecting the structure of the brain. Protein,

known as 'clumps' and 'tangles', start to form which damage the brain cells.

**Vascular dementia** is the second most common form, accounting for approximately 20 per cent of all cases. It is caused when stroke or small vessel disease affects the blood supply to the brain. **This factsheet focuses on vascular dementia.**

**Frontal temporal lobe dementia** occurs when the frontal and temporal lobes of the brain are damaged. It is a relatively uncommon form of dementia, and usually affects people under 65 years.

**Dementia with Lewy Bodies** results from changes in brain tissue. Tiny deposits of protein are found in nerve cells. Their presence in the brain interferes with its normal functioning and causes damage to brain cells.

### What is vascular dementia?

Vascular dementia affects over 111,000 people in the UK. It is caused when there are problems with the blood supply to the brain. In order to work properly, the **brain needs a**

**constant supply of blood.** Blood is delivered to the brain via a network of arteries and blood vessels, which are part of the vascular system. If there are problems within the vascular system and blood cannot reach the brain cells they will become damaged and eventually die.

A stroke can cause this type of damage. There are **two main types of stroke**.

An **ischaemic stroke** is caused by a blockage in the brain. This can happen when:

- a blood clot (thrombus) forms in a main artery to the brain, known as a cerebral thrombosis
- a blood clot, or fatty deposit, from another part of the body is carried in the bloodstream to the brain (called a cerebral embolism), or
- a blockage forms in the tiny blood vessels deep within the brain (called a 'lacunar stroke').

A **haemorrhagic stroke** happens when a blood vessel bursts, causing bleeding (a haemorrhage) either within, or on the surface of, the brain.

A **transient ischaemic attack (TIA)**, sometimes called a mini stroke, is similar to a stroke but the symptoms do not last as long, lasting from a few minutes to up to 24 hours.

### Types of vascular dementia

There are different types of vascular dementia.

#### Stroke-related dementia

This can occur from one large stroke and is

called single infarct dementia. An infarct is the term for an area of cells that have not received their blood supply and have died as a result.

#### Multi infarct dementia

This is caused by multiple mini strokes that take place over time giving rise to many tiny, widespread areas of damage. These strokes can be so small that a person may not know they are having them, in which case they are called 'silent strokes'.

#### Sub-cortical vascular dementia

Small vessel disease can cause vascular dementia. This disease is where small vessels deep within the brain become completely blocked (called lacunar strokes). Over time this damage can develop into sub-cortical vascular dementia. A doctor might use the term Binswanger's disease to describe this.

#### Mixed dementia

Another type of vascular dementia has recently been identified. Alzheimer's disease and vascular dementia can occur at the same time, known as mixed dementia (MD). Usually one of the two dementias will be more dominant and this one is most likely to be treated.

### What are the risk factors for vascular dementia?

One of the risk factors for vascular dementia is **stroke**. More than a quarter of people who have a stroke develop vascular dementia within three months.

Here are some general **risk factors** for developing vascular dementia. They are also risk factors for stroke:

- high blood pressure
- high cholesterol
- diabetes
- atrial fibrillation (a type of irregular heart beat)
- eating a high fat diet
- smoking
- drinking too much alcohol
- not doing enough exercise.

We have factsheets covering all these risk factors – contact us for copies.

Vascular dementia is **more common in men** and usually starts before the age of 75. It is also more common among Asian and Black Caribbean people. This may be because both groups are more prone to risk factors like high blood pressure and diabetes.

**Genetic conditions** can also increase your risk of developing vascular dementia. One such condition is **CADASIL**, an inherited disease, which occurs when thickening of blood vessel walls stops the blood supply to the brain. Usually affecting smaller vessels in the brain, it is a result of a change (mutation) in a gene. Symptoms associated with CADASIL are migraines and multiple strokes which usually start around the age of 30.

### What are the symptoms of vascular dementia?

Having **memory problems** (especially difficulty recalling recent events) is a well-known sign of dementia. This is not necessarily the case for vascular dementia as the symptoms depend on the part of the brain affected by the stroke. They include:

- weakness or paralysis on one side of the body
- incontinence

- balance problems and unsteadiness
- communication problems and difficulty following conversation
- mood changes such as depression.

**Not everyone affected by stroke will develop vascular dementia.** As dementia develops, a person's condition will deteriorate and worsen, unlike after a stroke. Vascular dementia tends to **worsen in stages**, with changes in a person's condition being 'stepped' rather than gradual. This means that often people with vascular dementia deteriorate suddenly with each new stroke and then make some improvement in between. If you have vascular dementia caused by small vessel disease, symptoms may develop more gradually.

As this disease progresses **other symptoms may develop** which will be similar to other forms of dementia. A person may:

- behave inappropriately by screaming and shouting, be restless or display repetitive behaviour
- have a tendency to wander
- have difficulty carrying out everyday tasks and may not look after their personal hygiene
- hide or lose things and accuse people of stealing
- become very forgetful and confused about times, dates and their surroundings
- see and hear things that aren't there (hallucinations)
- become angry and easily upset.

In the **later stages** of dementia, a person may not recognise their family and friends. They may need assistance to carry out household chores and personal tasks, and might not be able to express themselves or

understand what is said to them. Eventually someone may have to use a wheelchair or could become bedridden.

### Getting a diagnosis

If you think that you have vascular dementia, it is important that you **talk to your doctor**. It may help to **take a friend or relative with you** so that they can support you.

The first point of contact for most people is your **GP**. You may be then referred on to a **memory clinic**, a **neurologist** (brain specialist) or a **psychiatrist** who specialises in dementia for more tests and support.

To diagnose dementia correctly, you will have a **number of tests**. This will include a review of your personal and medical history (your doctor might ask you questions about your occupation, education and lifestyle), an assessment of your mental abilities, a physical examination including blood tests, a brain scan and a medication review.

To help assess your **mental abilities**, your doctor may use a questionnaire. There are a range of tests available, one of the most common is called the MMSE (Mini Mental State Examination). This will help test your memory, your ability to think, judge, remember and plan.

During your **physical examination** your doctor may check your blood pressure and cholesterol levels, check for heart problems and diabetes and look for weakness or numbness of limbs as this can be a result of stroke (if stroke has not already been diagnosed). They may also take blood and urine samples to help rule out other conditions like vitamin B12 deficiencies, thyroid problems, and low sugar levels.

You should also have a **brain scan**, either a CT or MRI scan, which will help establish if you have dementia and if so what type. If your doctor is still unsure what type you have, you may have a SPECT (single photon-emission computed tomography) scan. This will take pictures of your blood flow and will show any abnormalities in the brain.

### Treatment and support for vascular dementia

#### Information

After a diagnosis of dementia your **doctor should discuss your future treatment** and ways for you and your family to access support. Your doctor should tell you about:

- the signs, symptoms and prognosis for your condition
- any treatment available
- local care and support services
- legal advice
- driving.

#### Medication

Sadly, there is no treatment available to cure dementia but there are recommended **treatments that can slow its progression** such as donepezil, galantamine and rivastigmine. These drugs work by increasing levels of the chemical acetylcholine in the brain. Acetylcholine is a neurotransmitter that sends 'signals' from one cell to another and in people with dementia this becomes reduced.

Currently these drugs are **not available for people with vascular dementia**, but are used to treat Alzheimer's disease. They require more research and clinical trials before they can be approved for patients with vascular dementia in the UK. If you have **mixed dementia** (a combination of vascular

dementia and Alzheimer's disease), you may be eligible for this medication. To find out more please speak to your neurologist.

Though there is no specific treatment for vascular dementia, you may be prescribed **medication to reduce the risk of further strokes** and prevent further damage. This can include blood-thinning medicine like aspirin or warfarin to reduce the risk of clots forming, and medication to lower your cholesterol and blood pressure.

Your doctor may also give you advice on a **healthy lifestyle**, for example eating healthily (following a diet that is low in fat and salt), stopping smoking, taking regular exercise and only drinking alcohol in moderation. For more information, please see our factsheets, *F11, Blood thinning medication after stroke*, *F8, Healthy eating after stroke*, and *F6, High blood pressure and stroke*.

### Rehabilitation

Services like **physiotherapy, occupational therapy** and **speech and language therapy** can help improve any mobility or speech problems you may have as a result of stroke. If you live in Scotland, you may have an **exercise programme** tailored to your needs. This aims to help you to cope better and make the best of your abilities.

### Psychological support

Dementia can change your **behaviour** and ability to do everyday tasks. Some people can experience depression, memory problems, hallucinations, delusions, agitation, anxiety and aggression. They may wander or lack inhibition. Psychological support and cognitive behavioural therapy (CBT) can help. **Group therapy** using arts and crafts, music and reminiscence tools

may also help to alleviate these symptoms.

If you are distressed and anxious, massage, aromatherapy and animal assisted therapy can help relax and calm you. These may be available as part of a specialist dementia support service in your area (see page 6). People with **depression** may be offered anti-depressants, but only in the most severe case, as they can have profound effects on your cognitive ability. For more information, **talk to your GP**.

### Social services/ health and social care

If you or your loved one has dementia, you should make **full use of social services**. A social worker will **assess and plan the support you need at home**. They can help arrange nursing or residential care, organise payments you may be eligible for, provide aids and adaptations for your home (such as commodes, grab rails and walking frames), organise respite care services, and arrange for community meals and laundry services. Social services are part of your local council so you can find their contact details in your local phone directory or on your council's website.

### Local dementia support services

These services can also provide you with information and support. Often the help they give is invaluable to families and is another layer of support to those affected by dementia. They help make information more accessible, create opportunities to meet others affected by dementia, run day centres and activity clubs and provide emotional support. **Ask your GP** for details of local services and see the 'Useful organisations' section at the end of this factsheet.

### Finding out that you, or your loved one, has dementia

Coming to terms with a diagnosis of dementia can be very difficult for you and your family. If you have dementia, you may feel frightened about your future, frustrated, angry and upset with the changes in your abilities and behaviour and depressed. **You may need time to 'grieve' and come to terms** with the sense of loss you may be experiencing. All of these emotions are normal and natural.

Often, a close family member cares for a person with dementia. **If you are caring for someone with dementia, you too may feel a mixture of emotions.** You might feel unprepared for your role as a carer, overwhelmed by the changes in the person you are caring for, or exhausted by the physical and emotional demands of looking after someone. You might even feel anger and guilt for feeling this way. You are not alone; these emotions are normal and many dementia carers feel this way at some point.

A diagnosis of dementia can feel overwhelming, but many people feel reassured with the knowledge that it brings. It might explain strange things that have been happening to you and you can start to **prepare for the future.** Many people in the early stages of dementia live a relatively independent life and can continue to enjoy their life for some time.

#### What to do if you have dementia

Many people with dementia want to stay as independent as possible. **Accepting the practical and emotional support** that is offered by relatives and friends, social services, dementia charities and the NHS can help you achieve this.

You might want to live at home for as long as possible, but eventually you may have to move to a nursing home. Until that point ask an occupational therapist, clinical psychologist or social worker for **aid and adaptation ideas for your home** so you can **stay** as safe and mobile as possible. Your GP can refer you to these specialists. Taking as much responsibility as you can for your own health and care, with the support of others, can help ensure you have the best possible quality of life.

You can still **drive** after an early diagnosis of dementia, but you must inform the relevant driving agency that you have it (contact details are available at the end of this factsheet). You will eventually have to stop driving as your abilities become affected.

#### Tips to help

It is important to keep as active as possible; this will help you keep alert and interested in life. Try to keep up your hobbies, or try a new one like swimming, yoga or dancing – join a club or group so you are safe. Alternatively, you could play Sudoku, do word searches or crosswords or take up arts and crafts.

Maintain your friendships and social life. It is easy to feel lonely. Try and talk to people about how you are feeling. Make the first move if others find it difficult to talk to you about it. Alternatively find out about your nearest dementia support group and meet others who identify with how you feel. Peer support can be a tremendous help.

Become a creature of habit: leave your keys, wallet and phone in the same place; keep lists of useful contacts; pin weekly timetables in an obvious place; write down reminders; label things and keep a diary. Stay as safe as possible at home. Think

about alarms and devices that will protect you from danger, like smoke alarms or a personal alarm.

Contact a dementia charity for more support and ideas to help you maintain your independence. See 'Useful organisations' at the end of this factsheet.

### Caring for someone with dementia

Caring for a loved one with dementia is a kind, admirable and selfless act. At times, however, it may feel like an overwhelming and challenging responsibility.

It is very easy to become socially isolated as a carer. The **demands of the role** and your concerns for the person if left alone can stop you from meeting up with friends and family. Everyday caring tasks like washing, dressing and feeding may feel tough and frustrating.

**New roles and responsibilities** may fall at your feet like managing money and bills, which can be overwhelming. Many carers often sacrifice their own health and needs for the person they are looking after. It is common for dementia carers to have depression.

#### Tips to help

- Develop routines and structures as part of your day. Include your loved one in daily tasks like putting the shopping away or doing the garden. This will make them feel useful and increase their self worth whilst helping you with your daily chores.
- Have a break. Make time to see your family and friends or pursue your own interests.
- Try and meet people who can identify

with how you are feeling. Speaking to other dementia carers can be invaluable. Find out your nearest carers or dementia support service. Alternatively look online for chat forums and other social networks where you can meet people.

- Having time out from your role to relax is important. Find out about day care services, short-term residential care and whether you are eligible for assistance from social services. Ask for a carer's assessment.
- Coping with difficult behaviour can be very hard and leave you feeling helpless. Try and establish why this is happening. Is the person you are caring for reacting to something? Try and stay calm, take a breather from the situation and look for a solution.
- Try not to be critical. Encourage and reassure the person you are looking after.
- Look after yourself; eat healthily, exercise regularly if you can, and have regular check ups with your GP.
- Contact a dementia or carers' organisation for more support and ideas to help you. See our factsheet *F4, Stroke: a carer's guide* for more information.

### Finances and legal matters

If you have dementia, it is important to get financial and legal matters organised whilst you are still able to make decisions. By doing so, you are **ensuring that your future will be how you want it to be**.

You might like to consider making a **Lasting Power of Attorney (LPA)**, using an existing

**Enduring Power of Attorney** or creating a **will**. LPA allows you to appoint someone (a family member, friend or unpaid carer) to make decisions about your property and finances or your health and welfare if, in the future, you are unable to do so. This person is called an attorney and you can appoint more than one. There are two types of LPA. A property and affairs LPA will make decisions about your income, bills and the sale of your house (according to the conditions you may have decided). The second type, a personal welfare LPA, will make decisions on where you live, day-to-day care or medical treatment you may receive.

**You must be mentally well to set up a LPA.** If your loved one has lost their mental capacity, you can apply to take over their finances and become a deputy. If you live in England and Wales, you apply to the Court of Protection. This specialist court is for all issues relating to people who lack capacity. If you are in Scotland, you will apply to the Scottish Office of the Public Guardian. In Northern Ireland, you apply to the Office for Care and Protection. Contact details are listed at the end of this factsheet.

**Enduring Power of Attorney** allows a person you choose (an attorney) to make decisions about your property and finances. The attorney can make decisions whilst you still have mental capacity as well as when you lack capacity. Enduring Power of Attorney was replaced by LPA but is still valid if made and signed before October 2007.

By creating a **will** you can decide what will happen to your possessions after your death. There is no legal requirement to make a will but many people do so for peace of mind. A solicitor can help you. If you lack the

ability to make one and you do not have a will, the Court of Protection can make one for you. For information about our free wills scheme, see our contact details below.

### Useful organisations

All organisations are UK wide unless otherwise stated.

#### **Stroke Association**

**Stroke Helpline:** 0303 3033 100

**Website:** [stroke.org.uk](http://stroke.org.uk)

**Email:** [info@stroke.org.uk](mailto:info@stroke.org.uk)

Contact us for information about stroke, emotional support and details of local services and support groups.

#### **Carers' organisations**

##### **Carer's Direct (NHS)**

**Helpline:** 0808 802 0202

**Email:** [carersdirect@nhschoices.nhs.uk](mailto:carersdirect@nhschoices.nhs.uk)

**Website:** [www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)

Offers information, advice and support for carers.

##### **Carers UK**

**Tel:** 0808 808 7777

**Website:** [www.carersuk.org](http://www.carersuk.org)

Offers information and support for carers.

##### **Crossroads Care (England and Wales)**

**Tel:** 0845 450 0350

**Website:** [www.crossroads.org.uk](http://www.crossroads.org.uk)

##### **Crossroads Caring for Carers (Northern Ireland)**

**Tel:** 028 9181 4455

[www.crossroadscare.co.uk](http://www.crossroadscare.co.uk)

##### **Crossroads Caring Scotland**

**Tel:** 0141 226 3793

**Website:** [www.crossroads-scotland.co.uk](http://www.crossroads-scotland.co.uk)

Charity providing home-based respite support through trained care assistants.

### **The Princess Royal Trust**

**Website:** [www.carers.org](http://www.carers.org)

Has developed a UK-wide network of carers' centres to support family carers.

### **Dementia support services**

#### **Alzheimer's Scotland**

**Website:** [www.alzscot.org](http://www.alzscot.org)

**Helpline:** 0808 808 3000

Has a 24-hour helpline, day centres, home support, drop in centres, support groups, one to one support and information.

#### **Alzheimer's Society**

**Helpline:** 0845 300 0336

**Email:** [enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)

**Website:** [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Provides free information, advice, online forums and a helpline service to people affected by dementia. They have local support services, cafes and workshops.

#### **Dementia UK**

**Tel:** 020 7874 7200

**Email:** [info@dementiauk.org](mailto:info@dementiauk.org)

**Website:** [www.dementiauk.org](http://www.dementiauk.org)

Helped develop Admiral Nursing services that are specifically trained to support families affected by dementia. Provides information, advice and support to people with factsheets and a helpline service.

#### **Disabled Living Foundation**

**Helpline:** 0845 130 9177

**Website:** [www.dlf.org.uk](http://www.dlf.org.uk)

Provides specialist, impartial advice and an information service for those who need aids and equipment.

### **Driving agencies**

#### **Driver and Vehicle Licensing Agency (DVLA) Drivers Medical Group (England, Scotland, Wales)**

**Tel:** 0300 790 6806

**Email:** [eftd@dvla.gsi.gov.uk](mailto:eftd@dvla.gsi.gov.uk)

**Website:** [www.dvla.gov.uk](http://www.dvla.gov.uk)

Produce a 'Customer Service Guide' for drivers with Medical Conditions and an 'At a Glance Guide to the Current Medical Standards of Fitness to Drive'.

#### **Driver and Vehicle Agency (Northern Ireland)**

**Tel:** 0845 402 4000

**Email:** [dvlni@doeni.gov.uk](mailto:dvlni@doeni.gov.uk)

**Website:** [www.dvlni.gov.uk](http://www.dvlni.gov.uk)

The driver, vehicle and vehicle operator licensing authority in Northern Ireland.

### **Legal organisations**

#### **Office of the Public Guardian**

**Tel:** 0300 456 0300 **Email:**

[customerservices@publicguardian.gsi.gov.uk](mailto:customerservices@publicguardian.gsi.gov.uk)

#### **Court of protection**

**Tel:** 0300 456 4600

Information on both these subjects can be found on the government website: [www.direct.gov.uk](http://www.direct.gov.uk)

#### **Office of the Public Guardian (Scotland)**

**Tel:** 01324 678300

**Website:** [www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)

For information on Power of Attorney.

#### **Office for Care and Protection (Northern Ireland) Tel:** (028) 9072 4733

**Website:** [www.courtsni.gov.uk](http://www.courtsni.gov.uk)

Supports and promotes decision making for those who lack capacity or would like to plan for their future.

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**Disclaimer:** The Stroke Association provides the details of other organisations for information only. Inclusion in this factsheet does not constitute a recommendation or endorsement.

Produced by the Stroke Association's Information Service.

For sources used, visit [stroke.org.uk](http://stroke.org.uk)

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Factsheet 29, version 01 published April 2012

(next revision due March 2014)

Item code: **A01F29**



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