

# Care after stroke or transient ischaemic attack

Information for patients  
and their carers



CLINICAL  
EFFECTIVENESS &  
EVALUATION UNIT



Royal College  
of Physicians  
Setting higher medical standards

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This booklet is based on the **National Clinical Guideline for Stroke**, third edition, which includes the National Institute for Health and Clinical Excellence recommendations for management of acute stroke and transient ischaemic attack.

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## Who the booklet is for and what it covers

This booklet is about the care and treatment of adults after a stroke or a transient ischaemic attack (also called a TIA or 'mini-stroke'). It is written for adults who have had a stroke or TIA and their families and carers, but it may also be useful for anyone with an interest in the condition.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It does not describe stroke or TIA or the tests or treatments for these in technical detail. If you or someone close to you has a stroke, the healthcare team should discuss the care and treatment options with you. There are examples of questions you could ask in this booklet to help you with these discussions. Some sources of further information and support are on pages 24–31. Medical terms printed in **bold type** are explained on page 24.

The information in this booklet is based on detailed clinical guidelines for stroke produced primarily for healthcare professionals and published in the Royal College of Physicians (RCP) *National clinical guideline for stroke*, 3rd edition,<sup>1</sup> which includes the recommendations from the National Institute for Health and Clinical Excellence (NICE) guideline on the management of acute stroke.<sup>2</sup> The broad areas covered by the RCP guideline<sup>1</sup> and by the NICE guideline<sup>2</sup> are shown on page 23.

## Principles of care for people who have had a stroke or TIA

Treatment and care after a stroke or TIA should take into account your personal needs and preferences. You have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, they should give you (and where appropriate your family or carer) information you can understand and that is relevant to your circumstances.

They should take account of specific issues which affect many people with stroke such as speech and language difficulties, and problems with attention, concentration and memory which make understanding and retaining complex information difficult. This is in addition to any problems with sight, hearing, learning disabilities or English language which may have been present prior to the stroke. All healthcare professionals should treat you with respect, sensitivity and understanding, and explain stroke and TIA and the treatments to you simply and clearly.

Any treatment being suggested should take account of any religious, ethnic or cultural needs you may have. If you are unable to understand a particular issue or are not able to make decisions for yourself, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website ([www.dh.gov.uk/consent](http://www.dh.gov.uk/consent)). Healthcare professionals should also follow the code of practice for the Mental Capacity Act 2005. For more information about this, visit [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk) and see section 6.35 in the full guidelines.<sup>1</sup>

Sometimes a person who has had a stroke needs urgent treatment, and the medical staff may not have time to fully discuss what is involved with you or your family or carers beforehand. In these circumstances, detailed discussions and explanations may have to wait.

## **Description of stroke and TIA**

A stroke occurs when the blood flow to part of the brain is cut off – it is a ‘brain attack’ (in the same way that a heart attack happens when the blood supply to the heart muscle is cut off). Without a blood supply, brain cells can be damaged or destroyed because they may not receive enough oxygen.

The brain controls everything that the body does, so a stroke can affect many different functions of the body depending on which part of the brain is involved. The symptoms of stroke can include numbness, weakness or lack of movement on one side of the body, slurred speech, difficulty finding words or understanding speech, sudden problems with vision, confusion, and a severe headache. A stroke happens suddenly and the effects are experienced straightaway.

There are two main types of stroke. The most common type (an **'ischaemic' stroke**) is when one of the blood vessels leading to or in the brain is blocked. The second type (**'haemorrhagic' stroke**) is when a blood vessel in the brain bursts, causing bleeding into the brain.

A **transient ischaemic attack (TIA)**, often called a 'mini-stroke', happens when the blood supply to part of the brain is interrupted for a very short time. The symptoms are the same as for a stroke, but they usually last only a few minutes or hours, and have disappeared completely within 24 hours.

The NICE guideline<sup>2</sup> on stroke describes the early treatment that a person who has had a stroke or TIA should receive, whereas the RCP guideline<sup>1</sup> describes what should happen when you first have a stroke, how services should be organised, rehabilitation and specific treatments in the first six months and beyond. It also covers how to prevent having another stroke or TIA – called secondary prevention. (See also page 23.) The recommendations are based on evidence about best medical, nursing and therapy practice.

## Assessment

### Finding out what is wrong (diagnosis)

Anyone who suddenly has symptoms that might be caused by a stroke or TIA should be assessed by a paramedic or other suitable person as soon as possible (before they arrive at hospital) using a test such as **FAST (Face Arm Speech Test)**. A check should be made to rule out low blood sugar (hypoglycaemia) as a cause of the symptoms.

On arrival at A&E or the stroke unit, the diagnosis of a stroke or TIA should be checked using an accepted test such as the **Recognition of Stroke in the Emergency Room (ROSIER)** test.

#### **Questions about finding out what is wrong (diagnosis). Some suggestions for questions you may want to ask.**

Please give me more details about what tests are being done.

What do these tests involve?

Where and when will these tests be carried out?

How long will it take to get the results of these tests?

What did the tests show?

Can you show me my brain scan and explain what it shows?

## Specialist early care for people who have had a stroke

If it is suspected that you may have had a stroke, you should be admitted to a specialist stroke unit, either directly or from A&E.

### Brain scan

All people who have had a stroke should have a type of brain scan. This should happen as soon as possible, and definitely within one hour of admission to hospital, if any of the following apply:

- ▶ your symptoms suggest that you may benefit from treatment to dissolve a blood clot (**'thrombolysis'**) or reduce blood clotting
- ▶ you were taking drugs to reduce blood clotting (**anticoagulants**) before the stroke
- ▶ you are prone to bleeding
- ▶ you are unconscious
- ▶ your symptoms are varying or getting worse for no obvious reason
- ▶ you have a problem with your eyes called papilloedema, a stiff neck, or fever
- ▶ you had a very bad headache when the stroke symptoms began.

Otherwise the brain scan should be performed within 24 hours of your symptoms starting.

### Medication

#### **A drug for thrombolysis**

A 'clot-busting' drug called alteplase may be used if your brain scan indicates that it might help and hospital staff have had training for its use in stroke. This drug treatment is known as thrombolysis. However, treatment with alteplase must begin within three hours of stroke symptoms starting, and it should not be given to people under 18 or over 80 years old.

## **Aspirin and anticoagulants**

There are two types of drugs which are used to reduce the risk of blood clots forming (the cause of most strokes). The decision as to which sort you should have will be made after careful assessment by your medical team.

Everyone who has had a stroke should be given aspirin as soon as possible, and definitely within 24 hours of the stroke starting, unless your brain scan shows bleeding in your brain. You should continue to receive daily aspirin for two weeks or until you leave hospital, whichever is sooner. Your specialist should then discuss future treatment with you.

The table overleaf outlines the use of aspirin and anticoagulants.

## **Statins**

If you were taking a drug called a statin before your stroke to reduce your cholesterol, you should continue taking it

If you weren't already taking a statin you shouldn't be started on one immediately after a stroke. But if your stroke was caused by a blood clot and you have a blood cholesterol level of 3.5 mmol per litre or more, you should be started on a statin before you are discharged from hospital.

### **Questions about treatment. Some suggestions for questions you may want to ask your healthcare professional.**

Why have you decided to offer this particular type of treatment?

What are the pros and cons of having this treatment?

What will the treatment involve?

How will the treatment help? What effect will it have on symptoms?

How long will it take to have an effect?

Are there any risks associated with this treatment?

Are there any other treatment options available apart from the one you're recommending?

Is there any written material (like a leaflet) available about the treatment?

## The use of aspirin and anticoagulants.

Cause of stroke	Other considerations
Blockage of a blood vessel in the brain (ischaemic stroke)	The person must not have bleeding in the brain.
Blockage of a blood vessel	There is a high risk of the person developing a type of blood clot called a venous thromboembolism.
Blockage of a blood vessel	The person also has blood clots in their legs (deep vein thrombosis) or lungs (pulmonary embolism).
Blockage of the veins of the brain	The person might also have a bleed in the brain.
Blockage of a blood vessel	The person: <ul style="list-style-type: none"> <li>● was taking anticoagulants because they have replacement valves in their heart, <i>and</i></li> <li>● is at risk of bleeding in the brain.</li> </ul>
Bleeding in the brain (haemorrhagic stroke)	The person also has deep vein thrombosis or pulmonary embolism.
Bleeding in the brain	The person was taking anticoagulants before their stroke.

## Treatment\*

- ▶ Give aspirin as soon as possible, and definitely within 24 hours of the stroke starting.
  - ▶ The person should continue to receive daily aspirin for two weeks or until they leave hospital, whichever is sooner. Their specialist should then discuss future treatment with them.
  - ▶ If a person has had indigestion in the past associated with aspirin, a type of drug called a **proton pump inhibitor** should be offered as well as aspirin.
  - ▶ Anyone who has been shown to be allergic to or intolerant of aspirin should be given another **antiplatelet drug**, such as clopidogrel, instead.
- ▶ The patient may be given anticoagulants, and should be monitored closely.
- ▶ They should normally be given anticoagulants rather than aspirin.
- ▶ They should be given anticoagulants unless they have another condition that would make this unsafe.
- ▶ Their anticoagulant treatment should be stopped.
  - ▶ They should be given aspirin instead.
  - ▶ If it is safe they can start taking anticoagulants again after a week.
- ▶ They should be given anticoagulants rather than aspirin.
  - ▶ As an alternative to drugs, a device called a **caval filter** may be used.
- ▶ They should have treatment to reverse the effects of the anticoagulants.

\*Normally a person who has had a stroke should not be given anticoagulants unless there is a particular reason to do so, as listed here.

## Other care

### Nutrition and swallowing problems

You should be monitored by your healthcare team to make sure that you are getting enough food and fluids when you are in hospital.

You may have difficulty swallowing after having a stroke. You should have your swallowing assessed by a trained healthcare professional before you can have any food, liquid or medication by mouth. If you are unable to swallow, you should:

- ▶ be given food and fluids by a tube within 24 hours of being admitted to hospital
- ▶ be given medication by tube or suppository.

Your swallowing should be assessed by a specialist, preferably within 24 hours and definitely within three days of being admitted to hospital. After this assessment, you should be given food and fluids in a consistency or form that you can swallow. Further tests may be carried out if you continue to have problems.

## Surgery after stroke

A small number of people who have had a stroke will need an operation to help them recover.

## Preventing complications

If you have been severely affected by the stroke you may need:

- ▶ a special mattress designed to prevent pressure sores
- ▶ help to find comfortable positions so that you do not damage the side of your body affected by your stroke
- ▶ special equipment such as a hoist to ensure that you are moved safely

- ▶ chest physiotherapy to keep your lungs clear of infection.

As soon as you are able you should be helped to sit out of bed in an appropriate chair for short periods of time.

## Rehabilitation

### Principles of rehabilitation

Stroke rehabilitation professionals should assess what your needs are and then discuss what this means and work with you to help achieve as good a recovery as possible. This will be based on their assessment, your wishes and the severity of your stroke. All members of the team should provide a consistent approach so that you have the same advice and are given as much opportunity as possible to practise what you are advised to do repeatedly and in different settings.

The guidelines<sup>1</sup> recommend the following:

- ▶ In the early stages you should have as much therapy appropriate to your needs as you are willing and able to tolerate, and a minimum of 45 minutes every day in the early stages.
- ▶ Rehabilitation following your stroke should begin immediately. You will need care and advice from professionals with expertise in stroke rehabilitation. This will be designed to help you:
  - ▶ regain abilities lost or impaired after the stroke, eg walking, speech or use of your arm
  - ▶ find new ways of overcoming the disabilities that are slow or failing to recover, such as learning to write with the opposite hand
  - ▶ cope with problems with every day activities (referred to by the team as activities of daily living) including personal activities such as dressing, domestic activities such as cooking, and community activities such as shopping, hobbies and employment as appropriate to your circumstances before you had your stroke.

Further rehabilitation may involve:

- ▶ staying in the hospital where you were first admitted
- ▶ transferring to a rehabilitation unit elsewhere
- ▶ being discharged home with experts in stroke rehabilitation treating you at home, or visiting an outpatient department or day hospital as appropriate.

The rate of recovery tends to be most rapid in the first few weeks after stroke although rehabilitation can continue for many months. When rehabilitation no longer produces any marked improvement, it will usually be stopped but you should be reassessed at least once a year to see if a further course of rehabilitation would help. Just because therapy has stopped does not mean that you cannot continue to work on your own recovery, which may continue slowly for many years.

## Moving and walking

Your ability to move should be assessed as soon as possible after admission. The treatment you receive will depend on how much movement you have lost as a result of your stroke and on how active you were before you had it. Most people can sit up fairly quickly and will recover the ability to walk. Sometimes the stroke results in strange sensations, pain, numbness, weakness and muscle spasms. The rate and extent of recovery will be individual and varied, but improvement is usually most noticeable within the first six months. Assessment of your ability to move is usually carried out by a physiotherapist who should:

- ▶ tell you and your carer the results of the assessment
- ▶ decide with you and the stroke team how to help you regain as much movement as possible
- ▶ if necessary, teach your carer techniques for helping you to move safely in bed and around your home.

As you improve you may need advice on:

- ▶ whether it is safe to attempt walking and whether you should try to walk alone or with support from staff or your carer
- ▶ whether you might benefit from aids such as a foot support to help you walk
- ▶ safe, suitable aids to help you get about (eg the correct kind of wheelchair)
- ▶ the correct exercises to practise.

## Speaking, writing and understanding

Stroke can affect your ability to speak or understand what is being said (known as aphasia), and reading and writing may be difficult or impossible. You may be unable to speak clearly because of muscle weakness (known as dysarthria) or difficulty coordinating the complex placement of the speech muscles, eg struggling to place the tongue correctly in a sequence of sounds (known as apraxia or dyspraxia). Each individual may be affected in different ways such as:

- ▶ difficulty in speaking or producing any sounds at all
- ▶ problems in thinking of the right words to speak or write
- ▶ trouble understanding speech or writing
- ▶ use of nonsense words
- ▶ problems understanding humour
- ▶ difficulties with social rules such as taking turns to speak
- ▶ slurring of speech, sounding as if you are drunk
- ▶ gestures and facial expressions affected by paralysis.

The effects of your stroke on speech, reading and writing should be fully assessed by a speech and language therapist who will then:

- ▶ help you try to overcome problems with speaking, reading, writing or understanding what people say to you

- ▶ advise your relatives and the staff looking after you on the best ways of communicating with you
- ▶ consider your suitability for specific treatment programmes and monitor your progress.

If you have long-term language difficulties, your speech and language therapist can provide advice about whether you might benefit from further therapy, such as group communication programmes, and aids that may help you to communicate.

## Bladder and bowel control

It is quite common to find that you are unable to control your bladder and/or bowel movements after a stroke. Difficulty controlling when you pass urine is called urinary incontinence. Difficulty with bowel control is called faecal incontinence. The nursing staff should assess the causes and discuss the best way of managing how to minimise the effects of incontinence and produce a plan for you individually.

If you already had a catheter prior to the stroke it is likely to still be required in the long term. If you have not had a catheter before, however, it should only be used if you are unable to pass water, not as a means of treating incontinence. This can be distressing if you are embarrassed but there are alternatives which are more appropriate as it is often only a problem in the early stages.

Most patients regain bowel and bladder control in a few weeks. If you still have problems when you leave hospital, you and your carer can get advice from the hospital, your GP or community continence nurse advisor about:

- ▶ treatment and management of incontinence
- ▶ the range of equipment available to help with incontinence
- ▶ local services available to help you manage at home
- ▶ what equipment will be provided, by whom and who will pay for it.

An organisation call **Incontact** runs a helpline staffed by continence specialist nurses (contact details on the back of this booklet).

## The senses (vision, sensation and pain)

The senses can be affected in a number of ways after stroke. As with the other problems following stroke, these may recover spontaneously.

- ▶ Sometimes people lose some or all of the ability to see out of part of one or both eyes (called hemianopia). This should be assessed and if this causes practical problems you should be taught ways of compensating.
- ▶ There can be problems with pain especially in the shoulder and it is important that you tell staff about any pain you are experiencing so that they can find out the cause, put in place measures to prevent it (eg positioning your arm or using supports), give pain relief, or consider other treatments if appropriate (such as high intensity nerve stimulation or strapping). If it is a more general pain and persists for several weeks it may be necessary to see a specialist in pain management.
- ▶ You may experience a loss of sensation down one side. This should be assessed and, especially if you are able to move the limb but it is numb, you need to be shown how to take care of it to avoid injuring yourself accidentally.

## Getting back to a normal life

It is common after a stroke for some people to have difficulty with common everyday activities such as dressing, cooking, shopping, hobbies and employment. You should be assessed by an occupational therapist for these problems to find out what sort of therapy will best help you. This may involve:

- ▶ advice on strategies to avoid doing things that are unsafe (eg getting into too hot a bath, cutting yourself shaving)
- ▶ practising some of the activities with help and guidance from the therapist and nursing staff (eg dressing, cooking)

- ▶ special equipment to make activities like feeding, dressing or bathing easier for you
- ▶ arranging for adaptations to be made to your home to make it easier for you to carry on as normal a life as possible. This may mean that the occupational therapist visits your home to see what is required, so that arrangements can be made for any work to be carried out by your local social services department before you go home.
- ▶ If you are a driver you will be advised about driving and informed that continuing to drive is dependent on satisfactory recovery. If you have a group 1 licence (ie ordinary licence) you should be informed that you must not drive for a minimum of four weeks. If you have a group 2 licence (eg for a heavy goods vehicle) you must inform the Driver and Vehicle Licensing Agency (DVLA) and you will not be allowed to drive under this licence for at least 12 months.

## **Transferring from hospital to home**

When you are transferred either home or to another hospital or care home, it should happen without delay and the healthcare teams in hospital and in the community should make sure that all the information is transferred, including medication, so that you don't have to give complex information to many different people. You should be involved in making decisions about the transfer and be offered copies of transfer documents. You should not be discharged early from hospital to non-specialist services unless there is continuing involvement from the specialist stroke services. You should be told how to contact these specialist services when you leave and health and social services should ensure that you can access support and advice easily, for example using a single point of contact.

## Family involvement

It is up to you to decide how much you want your family members to be involved in discussions about the stroke and how to manage afterwards. If you decide that you want them to be included in all important decisions, they should be given detailed information about your stroke, and about how much recovery you can expect to make. They should be taught how to help and support you and how to look after you, and what to do to avoid your having another stroke. They should be given clear guidance on how to seek help if problems develop.

## Emotional and psychological effects of stroke

It is very common for strokes to cause problems with thinking, concentrating, remembering, making decisions, reasoning, planning and learning. After a stroke nearly everyone feels tired and it may take many months to regain normal energy levels. You may also have problems with your mood. These may take the form of feeling emotional, anxious, unhappy or depressed (sometimes crying or laughing uncontrollably), or involve difficulties relating to other people. You and your relatives should receive advice and help about all these problems, including:

- ▶ opportunities to talk about the impact of your stroke on your life, including family and sexual relationships
- ▶ explanations about the possible psychological effects of stroke
- ▶ checking for depression and anxiety within the first month of your stroke
- ▶ ongoing review of any problems with depression or anxiety, or your emotions.

For many people, symptoms settle down over time and do not necessarily improve with drug treatments. However, if your symptoms are severe or last a long time, you may benefit from a referral to a clinical psychologist or

psychiatrist for expert help. This service is part of the NHS and you can be referred by your GP or the stroke physician in charge of your care.

## Transient ischaemic attack (TIA)

### Treatment after a TIA

If you have recently had stroke-like symptoms that disappeared quickly, they could have been caused by a TIA. A TIA should be treated as an emergency. You should get medical advice as soon as possible because you may have a greater risk of having a major stroke in the near future.

You should have your risk of stroke assessed as soon as possible with a scale that takes into account your age, blood pressure, and type of symptoms and how long they lasted (**ABCD<sup>2</sup> score**).

**An ABCD<sup>2</sup> score of 4 or above means that you have a high risk of stroke in the near future. If you have had two or more TIAs in a week and are taking anticoagulants you are at high risk.**

If you are at high risk of stroke, you should be started immediately on daily treatment with aspirin. You should see a stroke specialist within 24 hours of when your symptoms started. If your specialist is unsure which area of your brain was affected by the TIA, you should also have a brain scan within 24 hours. (If you need a scan, you will usually be offered a type of scan called **MRI (magnetic resonance imaging)** unless this is not suitable for you, in which case you should be offered a **CT (computed tomography)** scan.

If you are at lower risk of stroke, you should also be started on aspirin immediately. You should be assessed by a specialist as soon as possible, and definitely within one week. If you need a brain scan you should also have this within one week.

Once it has been confirmed that you have had a TIA, your healthcare team should talk to you about making changes to your lifestyle to reduce the risk of having a stroke. These changes might include stopping smoking, reducing the amounts of saturated fat, alcohol and salt in your diet, losing weight and taking more exercise.

## Further tests after a TIA or minor stroke

If you have had a TIA or minor stroke and your specialist thinks that the cause might be blockage of the main blood vessel in your neck (the **carotid artery**), you should have a scan of your neck within one week of when your symptoms started.

If the scan shows significant narrowing of your carotid artery, you should have an operation called a **carotid endarterectomy** within two weeks of your stroke or TIA to remove the blockage, if this is appropriate for your overall health.

Whether or not you need surgery, you should be given drugs to reduce blood clotting if you have any narrowing of the carotid artery. You should also be offered advice and/or drugs for controlling your blood pressure and reducing your cholesterol level.

## Prevention of further stroke or TIA

Once someone has had a TIA or stroke they are more likely to have another one. There are a number of things you can do, though, to reduce your risk of having another stroke. These may include:

- ▶ following advice on lifestyle (including advice on your diet, achieving a satisfactory weight, regular exercise, stopping smoking, reducing alcohol and salt intake)
- ▶ making sure your blood pressure is controlled within safe limits

- ▶ drug treatments to reduce the risk of blood clotting. Sometimes this is as simple as taking an aspirin a day, but may include other medication if you are allergic to aspirin, or prone to bleed easily, or your doctor thinks you would benefit from additional treatment, or if you have an irregular heart rhythm
- ▶ taking a statin to reduce your blood cholesterol.

To prevent another stroke occurring, it may be very important to continue with any of these measures for the rest of your life. If there are complications associated with any of them you should take professional advice, as there may be other ways of dealing with the problem.

## End of life

Unfortunately some individuals will not recover, either because the stroke is very severe or because it is combined with other health problems. If this is the case and death is inevitable, patients should have access to specialist palliative care. And all end-of-life decisions, including the withholding or withdrawal of life-prolonging treatments, should be in the dying person's best interests.

## References and guideline coverage

The RCP guideline<sup>1</sup> covers:

- ▶ how stroke services should be organised
- ▶ some aspects of the immediate management of stroke that are not covered by the NICE guideline below
- ▶ the immediate management of subarachnoid haemorrhage (bleeding over the surface of the brain)
- ▶ rehabilitation after stroke, both immediately after it has happened and for the months and years that follow
- ▶ the advice and treatment that are important to prevent further strokes from happening.

The advice in the NICE guideline<sup>2</sup> covers:

- ▶ how healthcare professionals should recognise the symptoms of a stroke or transient ischaemic attack (TIA) and make a diagnosis quickly in people over the age of 16 years
- ▶ when to use brain imaging and other types of scan
- ▶ specialist care for people in the first two weeks after a stroke
- ▶ drug treatments for people who have had a stroke
- ▶ surgery for people who have had a stroke.

- 1 Intercollegiate Stroke Working Party. *National clinical guideline for stroke*, 3rd edition. London: Royal College of Physicians, 2008.
- 2 National Collaborating Centre for Chronic Conditions. *Stroke and transient ischaemic attack: national clinical guideline for diagnosis and initial management of acute stroke and transient ischaemic attack (TIA)*. London: National Institute for Health and Clinical Excellence, 2008.

## Glossary

**ABCD<sup>2</sup> score:** a score that predicts the risk of a person having a stroke within a few days of a TIA.

**anticoagulant:** a type of drug that reduces blood clotting; examples include warfarin and heparin.

**antiplatelet drug:** a type of drug that helps prevent the formation of blood clots by affecting the function of blood cells called platelets; examples include aspirin and clopidogrel.

**carotid artery:** the main blood vessel in the neck that carries blood to the brain.

**carotid endarterectomy:** an operation to remove a blockage in the carotid artery.

**caval filter:** a device that is implanted in a blood vessel called the inferior vena cava in order to prevent the formation of a pulmonary embolism.

**CT (computed tomography) scan:** a type of three-dimensional scan that uses X-rays to give images of body tissues.

**deep vein thrombosis (DVT):** a blood clot that forms in a vein (usually in the leg).

**FAST (Face Arm Speech Test):** a test involving three simple checks to indicate whether a person has had a stroke or TIA.

**haemorrhagic stroke:** a type of stroke caused when a blood vessel bursts, causing bleeding into the brain.

**ischaemic stroke:** a type of stroke that happens when a clot blocks an artery that carries blood to the brain.

**MRI (magnetic resonance imaging) scan:** a type of scan that uses a strong magnetic field and radio waves to produce detailed pictures of the inside of your body.

**proton pump inhibitor:** a type of drug that treats indigestion by reducing the amount of acid produced in the stomach.

**statin:** a type of drug used to lower cholesterol levels.

**ROSIER (Recognition of Stroke in the Emergency Room):** a test used by healthcare professionals in A&E to confirm that someone has had a stroke.

**thrombolysis:** treatment with a drug that breaks down blood clots.

**transient ischaemic attack (TIA):** often called a 'mini-stroke', a TIA happens when the brain's blood supply is interrupted for a very short time.

## Useful organisations

### Local health services

Information about local health services for stroke patients should be available from your GP, local hospital, primary care trust, strategic health authority and local branches of the Stroke Association. You can get contact details for all these agencies from **NHS Direct** (Freephone: 0845 4647; website: [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)).

### Social services

Social services offer various types of information, advice or services to help people at home, in residential homes or nursing homes. Details of local social services departments are listed in your local telephone directory or are available from local council offices. If you meet certain criteria you may be eligible for services (which may carry a financial charge) such as:

- ▶ help with personal care
- ▶ meals
- ▶ equipment and aids to use at home, or adaptations to your home.

Some social workers are based in or attached to hospitals. If you think you will need help at home when you leave hospital and a social worker has not been organised for you, ask the hospital staff to contact a social worker from the community/district team for you. The social worker will then assess your needs for help and assistance. If you have an assessment by social services to determine your needs, your carer will also be eligible for an assessment of any needs for support with their care giving.

You may not be able to live in your own home after your stroke. Social services can help you choose the right residential or nursing home. Depending on your income level and any savings you have, they may also be able to organise some financial help with this.

## Financial help and advice

Having a stroke can affect your income, particularly if you have to give up work. The **Benefit Enquiry Line for People with Disabilities** (Freephone: 0800 88 22 00) provides general confidential advice about benefits and details of local branches of the **Department of Work and Pensions** whose staff can provide information and advice on benefits, grants and loans. In some areas, freephone language lines (advice in languages other than English) are listed in your local telephone directory. If you want help filling in forms to claim Disability Living Allowance (DLA) or Attendance Allowance, the Benefit Enquiry Line can pass your details on to the regional disability centres who will call you back to assist with this. Some regional disability centres may also organise home visits to complete forms for people with severe disabilities.

Local branches of organisations such as **Age Concern** and the **Citizens Advice Bureau** also offer advice on financial, legal and welfare matters.

Your local Employment Services JobCentre provides advice to help people with disabilities return to work. Many areas also have DIAL services (Disability Information and Advice Line) that provide advice, information and guidance for disabled people, including those who are seeking employment. The **Stroke Association** and **Different Strokes** (see below) also provide much useful advice and guidance. Some assistance may be available from charities that specialise in helping disabled people to return to work (eg the **Shaw Trust**, Tel: 0808 180 2003). The government website **Directgov** provides information across government departments and elsewhere for disabled people including employment support:

[www.direct.gov.uk/en/DisabledPeople/index.htm](http://www.direct.gov.uk/en/DisabledPeople/index.htm)

## Voluntary and support groups

(For contact details see pages 30–31)

### The Stroke Association

The **Stroke Association** provides practical support, including telephone helplines, publications and welfare grants, to people who have had strokes, their families and carers. In parts of the country, the Stroke Association provides a range of services including:

- ▶ family and carer support workers: people who offer emotional support and advice to families of people who have had strokes, and to people affected by stroke who live alone
- ▶ a community service called **Communication Disability Support**, where staff and volunteers work to improve communication skills with people who have lost the ability to speak, read or write.

Local health services should have contact details for local Stroke Association services and copies of their information leaflets.

Helpline: 0845 3033 100

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

### Different Strokes

**Different Strokes** is run by and for younger people who have had strokes. It produces information on a range of topics including general advice on disability aids and gadgets, benefits, social services, patients' rights, coping with the psychological impact of stroke, and the effects of stroke on sex and relationships. Their helpline is staffed by stroke survivors and they organise a nationwide counselling network. Local branches (where available) run regular exercise classes.

Tel: 0845 130 7172

Website: [www.differentstrokes.co.uk](http://www.differentstrokes.co.uk)

## **Connect – the communication disability network**

**Connect** works with people living with stroke and aphasia (problems with speech and language). Connect's vision is a world where aphasia is no longer a barrier to opportunity and fulfilment. Connect's practical work with people living with aphasia is backed by in-depth research, and together they form the basis for a comprehensive programme of education and training courses for health and social care providers as well as for people with aphasia, their families, friends and carers. Connect also produces books and resources to help people living with aphasia get information in formats that are easy to understand, such as *The stroke and aphasia handbook*.

Tel: 020 7367 0840

Website: [www.ukconnect.org](http://www.ukconnect.org)

## **Speakability**

**Speakability** is a national charity that supports people living with aphasia and their carers. They run an information service and special events throughout the year. Their main activity is a national network of support groups, run by people with aphasia for people with aphasia. The groups meet regularly for mutual support and social activities. They are not therapy groups.

Helpline: 080 8808 9572

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

## Local stroke clubs

There may be local stroke clubs in your area which provide advice, support and meetings for stroke patients and their carers. These may be organised by local GPs, district nurses or health visitors or by local branches of the Stroke Association or Different Strokes. Some local patients and carers set up their own clubs or self-help groups without input from formal organisations. Contact your GP, or members of your specialist stroke team, for details of local clubs and groups. You can then choose the one which provides the kind of meetings and activities which best suit your own personal needs.

## Carer groups

Similarly, your local health and social services should also have details of any local carer groups which cater specifically for relatives and friends caring for people with disabling conditions. Useful advice and information is also available from national organisations such as **Carers UK** (Tel: 020 7490 8818). The **Relatives and Residents Association** provides information, advice and support for residents of care homes and their relatives via a telephone helpline: 020 7359 8136; website: [www.relres.org](http://www.relres.org).

# Addresses, telephone numbers and websites

## **Benefit Enquiry Line for People with Disabilities**

Freephone: 0800 88 22 00

## **Carers UK**

20 Great Dover Street  
London SE1 4LX

Tel: 020 7490 8818

CarersLine 0808 808 7777

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

## **Chest, Heart & Stroke, Scotland**

65 North Castle Street  
Edinburgh EH2 3LT

Advice line: 0845 077 6000

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

## **Connect – the communication disability network**

16–18 Marshalsea Road  
London SE1 1HL

Tel: 020 7367 0840

Website: [www.ukconnect.org](http://www.ukconnect.org)

## **Different Strokes**

Different Strokes Central Services  
9 Canon Harnett Court  
Wolverton Mill

Milton Keynes MK12 5NF

Tel: 0845 130 7172

Website: [www.differentstrokes.co.uk](http://www.differentstrokes.co.uk)

## **Directgov**

Website: [www.direct.gov.uk/en/DisabledPeople/index.htm](http://www.direct.gov.uk/en/DisabledPeople/index.htm)

## **Disabled Living Foundation**

380–384 Harrow Road  
London W9 2HU

Helpline: 0845 130 9177

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

## **Incontact**

SATRA Innovation Park  
Rockingham Road  
Kettering  
Northants NN16 9JH

Specialist helpline:

0845 345 0165

Trained counsellor helpline:

0870 770 3246

General information:

01536 533 255

Website: [www.incontact.org](http://www.incontact.org)

## **NHS Direct**

Freephone: 0845 4647

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

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**Northern Ireland Chest, Heart  
& Stroke Association**

Belfast Office  
21 Dublin Road  
Belfast BT2 7HB  
Advice helpline: 028 9032 0184  
Website: [www.nichsa.com](http://www.nichsa.com)

**The Stroke Association**

Stroke House  
240 City Road  
London EC1V 2PR  
Helpline: 0845 3033 100  
Website: [www.stroke.org.uk](http://www.stroke.org.uk)

**Relatives and Residents Association**

24 The Ivories  
6–18 Northampton Street  
London N1 2HY  
Advice Line: 020 7359 8136  
Website: [www.relres.org](http://www.relres.org)

**Shaw Trust**

Fox Talbot House  
Greenways Business Park  
Malmesbury Road  
Chippenham  
Wiltshire SN15 1BN  
Tel: 0808 180 2003  
Website: [www.shaw-trust.org.uk](http://www.shaw-trust.org.uk)

**Speakability**

Helpline: 080 8808 9572  
Website: [www.speakability.org.uk](http://www.speakability.org.uk)

Patients, carers or health professionals who would like to purchase further copies of this booklet should go to the Royal College of Physicians website:

[www.rcplondon.ac.uk/pubs/brochure.aspx?e=250](http://www.rcplondon.ac.uk/pubs/brochure.aspx?e=250)

Physicians and others who would like to purchase copies of the full *National clinical guideline for stroke*, 3rd edition, should go to the Royal College of Physicians website:

[www.rcplondon.ac.uk/pubs/brochure.aspx?e=250](http://www.rcplondon.ac.uk/pubs/brochure.aspx?e=250)

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