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Who is this booklet for and what does it cover?

This booklet is for people who have had a stroke or transient ischaemic attack (TIA) and their relatives and friends who care for them. It explains how people with stroke should be treated. It will not answer all your questions but will help you to understand: what a stroke is; some of the effects of stroke and its treatments; how stroke care should be organised; and where to get more information and advice. The information is based on detailed clinical guidelines produced primarily for health professionals which are available from the Royal College of Physicians (see page 23), and are on their website:

www.rcplondon.ac.uk

If you have any questions about the information in this booklet or about your own treatment and care, please do not hesitate to ask the staff responsible for caring for you or your relative.

What is a stroke or a transient ischaemic attack (TIA)?

A stroke is a type of brain injury. Every stroke is different and people who have strokes are affected in different ways, ranging in severity from getting better within 24 hours, known as transient ischaemic attack (or TIA), to a stroke which may cause severe damage or even death. Symptoms depend on the part of the brain that is affected. There are two main types of stroke:

- 1 The most common type ('ischaemic' stroke) happens when blood vessels to the brain are blocked by a clot or become too narrow for blood to get through to the brain. The reduced blood flow causes brain cells in the area affected to die from lack of oxygen.

2 In a 'haemorrhagic' stroke, the blood vessel is not blocked but it bursts and blood leaks into the brain causing damage. One particular type of haemorrhage is where most of the bleeding is onto the surface of the brain and this is called subarachnoid haemorrhage.

A transient ischaemic attack (TIA) is less severe than a stroke in that all the symptoms disappear within a day (and usually last for less than half an hour).

When a stroke happens, some brain cells are damaged and others die. Brain cells which die cannot start working again. However, those just outside the area of the dead cells may recover as the swelling caused by the stroke goes down. Recovery can also occur as other parts of the brain take over from areas that died.

Stroke affects people in different ways. Some people experience a few mild effects which improve in a short time (sometimes only minutes or hours). Others suffer many severe effects which last for months or even years. The effects of your stroke will depend on the part of your brain that has been injured or damaged, how bad the injury is, and your general health at the time of your stroke. Recovery can continue for several years after the stroke. Recovery may also be helped by learning ways of adapting to disability.

How is stroke care organised?

Your local stroke service should have a stroke unit, providing care in hospital. There should also be services for outpatients and for rehabilitation in the community. Wherever you are cared for, you should receive care from a range of professionals with specialist knowledge of stroke and rehabilitation. Your stroke team may include hospital doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, social workers, family care support workers and your GP, all of whom work together as a multidisciplinary team to respond to your own particular needs.

Services for younger people with stroke

Although stroke is most common in people over 65 years old, a significant number of younger people also suffer stroke. If you are a younger stroke patient, you may not fit easily into standard services. You should have access to medical and rehabilitation services which recognise your particular medical, rehabilitation and social needs. There is an organisation which supports young stroke survivors called **Different Strokes. The Stroke Association** also runs special stroke groups for young people. (For both organisations, see page 21 and back of booklet.)

How do I recognise a TIA or stroke?

The common symptoms of TIA are:

- ▶ weakness affecting one side of the body
- ▶ loss of vision in one eye
- ▶ loss of speech (either understanding what is being said or being able to produce the right words, or slurring of speech).

The symptoms may resolve within minutes and have always completely gone within 24 hours. TIA does not usually cause falls, blackouts, dizziness or memory loss. Although the symptoms of a TIA may be less severe than those of a stroke, you should seek medical advice quickly. At the time it may be hard to tell whether it is a TIA or a stroke.

Symptoms that might suggest you are having a stroke include all those described for TIA. The difference is that they will persist for longer than 24 hours. Don't wait to see if it's a stroke or TIA before seeking medical advice.

What treatment should I have after a TIA?

A TIA should be seen as a warning sign that a stroke may be imminent. Between 10 and 20% of people who have a TIA will have a stroke within a month. You should see your GP or go to the local hospital casualty department as quickly as possible.

- ▶ Within a maximum of seven days, you should expect to be referred to a specialist clinic, and be investigated and treated for the underlying cause of the TIA.
- ▶ You may need a brain scan and a scan of the arteries in your neck.
- ▶ You will need a blood test to check your cholesterol level.
- ▶ You may be advised to change your diet to reduce salt and fats.
- ▶ You may need to start taking more exercise.
- ▶ You will probably be started on tablets to lower your blood pressure and cholesterol, as well as a tablet to reduce the risk of blood clots.
- ▶ A small number of people who have a TIA will be advised to have an operation (called carotid endarterectomy) to improve the blood flow to the brain.

What treatment should I have after a stroke?

If symptoms suggest that you are having a stroke you should dial 999 immediately, and ask for an ambulance.

Most patients should be admitted to hospital for initial care and assessment. You should be cared for in a stroke unit or ward specially geared for patients with stroke, with staff trained in the care of stroke patients.

Very occasionally it will be decided not to admit someone to hospital after a stroke. If you are cared for at home, you and your carers should be given information about services you might need (eg about emergency services available, contact arrangements for help and advice, quick and easy access to specialist stroke services).

Care in the early stages may include some of the following:

- ▶ finding out what the problem is and the type of stroke you have had, the area of damage and how serious it is (diagnosis)
- ▶ having a brain scan as soon as possible and certainly within 24 hours to help with diagnosis
- ▶ receiving drugs to help dissolve the blood clot (thrombolysis). Not all units offer thrombolysis, and even in units that do, only a small proportion of patients are suitable for this treatment. To be effective, the quicker the drug is given the better. The patient has to receive the drug within three hours of developing the symptoms, in order for it to work.
- ▶ a referral to a brain surgeon for assessment if you have had a subarachnoid haemorrhage
- ▶ preventing or treating medical problems and complications, and trying to stop your stroke from getting worse.

Once your stroke has been diagnosed, trained staff will assess the effects your stroke has had on you and your abilities, and work out a plan of care for you.

Alertness and the ability to think

The extent to which you are awake and alert, or alternatively unconscious, should be assessed on admission. If conscious (or when you regain consciousness), you will then be assessed for any problems in your thinking, your memory or concentration, and how aware you are of your surroundings.

Swallowing and eating

After a stroke many people have problems swallowing fluids or food (called dysphagia). Your swallowing should be assessed as soon as possible. Assessment involves a simple test; for example you may be asked to try to swallow a small amount of water. If you have problems swallowing, a speech and language therapist or specialist nurse will carry out further tests and advise you and the staff looking after you on techniques for safe swallowing and on the consistency of food and fluids you should be given.

You should also be assessed to see if you are eating enough. If you have problems eating or swallowing your food, you may need to be referred to a dietitian. If you are not able to eat enough food by mouth, you may need to be fed temporarily through a tube.

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 the lungs clear.

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

What should I expect from rehabilitation?

Rehabilitation following your stroke should begin immediately. You will need care from specialist stroke services which provide rehabilitation. This will be designed to help you:

- ▶ regain abilities lost through stroke, for example helping you to walk, talk or use your arm again
- ▶ find new ways of coping with disabilities that are slow to recover, such as learning to write with the opposite hand
- ▶ cope with problems with daily activities including personal activities (eg dressing), domestic activities (eg cooking), community activities (eg shopping), hobbies and employment
- ▶ cope after discharge from hospital by giving you social, emotional and practical support.

Further rehabilitation may involve:

- ▶ staying in the hospital you were first admitted to
- ▶ transfer to another hospital or unit which specialises in rehabilitation
- ▶ discharge home with specialist stroke rehabilitation provided for you at home, at a hospital outpatients department or at a day hospital.

The kind of rehabilitation you have will depend on your needs, which should be assessed to see which treatments and therapies are needed to bring about as good a recovery as possible. You may not need rehabilitation if your stroke was mild or you recover fully in a short space of time. 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 patients 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. It is important to remember that you will recover in many different ways. 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, write and understand what is being said. This is known as aphasia and can affect people 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.

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.

The **Continence Foundation** runs a helpline staffed by continence specialist nurses (for contact details, see back of booklet).

The senses

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 one side. If you do have this problem you should consult your doctor before driving.
- ▶ There can be problems with pain or loss of sensation down one side.

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
- ▶ advice from your doctor about driving.

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. Nearly everyone after a stroke feels tired and it may take many months to regain normal energy levels. You may 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 with 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
- ▶ screening 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 like these 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.

How do I prevent 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, and 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 tablet to reduce the cholesterol in your blood.

To prevent another stroke occurring, it is very important to continue with 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.

What about the long term?

What help can my friends and family have when I go home?

Stroke affects not only the patient but their whole family. Relatives and carers can obtain information and support from several organisations named on the back of this booklet, as well as from health and social services staff. If you are a relative or carer, you can ask if the following are available locally:

- ▶ a named person to contact for advice, especially after discharge from hospital
- ▶ an information pack which tells you how to get in touch with local services that can support you in your role as a carer
- ▶ a local stroke group, stroke club or carer support group. Groups vary in what they provide but activities may include social gatherings, exercise classes, swimming outings or speech therapy for patients; advice and practical help for carers. There may also be local groups catering specifically for younger stroke patients.

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

Social services

Social services offer various types of information, advice and 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 and 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, including (in certain areas) food for ethnic minorities
- ▶ 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 their needs for support with 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 **Benefits 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 & 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 Benefits 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 Service JobCentre Plus 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** 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 01225 716350, and **Opportunities**, Tel 020 7448 5420).

Voluntary and support groups*

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 some parts of the country, the Stroke Association provides:

- ▶ family 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 **Dysphasia Support**, where 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. Alternatively, you can phone the Stroke Association Helpline: 0845 30 33 100.

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.

*For contact details, see back of booklet.

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 access information in formats that are easy to understand, such as *The aphasia handbook*.

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.

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 (0808 808 7777)**. **The Relatives and Residents Association** provides help and advice for people in long-term care (long-stay hospitals, residential homes and nursing homes) and their families (020 7359 8136).

Patients or carers requiring further information or copies of this booklet should contact the Stroke Association on 0845 30 33 100 or they can find it on the Royal College of Physicians website at www.rcplondon.ac.uk/pubs/books/strokecare

Physicians and others who would like to purchase further copies in bulk or the full *National Clinical Guidelines for Stroke*, 2nd edition, should contact the Publications Department at the Royal College of Physicians.

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Addresses and telephone numbers

Benefits Enquiry Line for People with Disabilities

Tel: 0800 88 22 00

British Brain and Spine Foundation

7 Winchester House

Kennington Park

Cranmer Road

London SW9 6EJ

Helpline: 0808 808 1000

Website: www.bbsf.org.uk

Chest, Heart & Stroke, Scotland

65 North Castle Street

Edinburgh EH2 3LT

Adviceline: 0845 077 6000

Website: www.chss.org.uk

Continence Foundation

307 Hatton Square

16 Baldwins Gardens

London EC1N 7RJ

Helpline 0845 345 0165

Website: www.continence-foundation.org.uk

Connect – the Communication Disability Network

16–18 Marshalsea Road

Borough

London SE1 1HL

Tel: 020 7367 0840

Website: www.ukconnect.org

Different Strokes

9 Canon Harnett Court

Wolverton Mill

Milton Keynes MK12 5NF

Helpline: 0845 130 71 72

Website: www.differentstrokes.co.uk

Disability Information and Advice Line (Dial UK)

St Catherine's

Tickhill Road

Doncaster

South Yorkshire DN4 8QN

Tel: 01302 310 123

Website: www.dialuk.info

Disabled Living Foundation

380 Harrow Road

London W9 2HU

Helpline: 0845 130 9177

Website: www.dlf.org.uk

Northern Ireland Chest, Heart & Stroke Association

22 Great Victoria Street

Belfast BT2 7LX

Advice Helpline: 028 9026 6710

Website: www.nichsa.com

Speakability

Canterbury House

1 Royal Street

London SE1 7LL

Helpline: 080 8808 9572

Website: www.speakability.org.uk

The Stroke Association

Stroke House

240 City Road

London EC1V 2PR

Stroke Helpline: 0845 30 33 100

Website: www.stroke.org.uk