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Chest, Heart and Stroke Scotland is an autonomous Scottish Charity. We receive no government funding and rely entirely on public subscription to fulfil our programme of activities.

We need £4 million a year to fulfil our commitment to improving lives for Scottish people. We need your help and your money to help others. You can help by volunteering your time as a fundraiser, VSS volunteer or support your local Regional office. You can send a donation, remember us in your Will, take out a Deed of Covenant or organise a fundraising event.

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STROKE SERIES SS1

STROKE: A GUIDE TO YOUR RECOVERY

If you would like to speak to one of our Advice Line nurses, in confidence, phone the Chest, Heart and Stroke Scotland Advice Line

Monday – Friday
9.30am - 12.30 and 1.30pm - 4.00pm

0845 077 6000

Email: adviceline@chss.org.uk
Textphone available

Registered Charity No.SCO18761

May 2004





Chest, Heart & Stroke Scotland, is an independent medical charity which aims to improve the quality of life for people in Scotland affected by chest, heart and stroke illnesses, through medical research, advice and information and support in the community.

FUNDRAISING

CHSS is an independent Scottish medical charity. We receive no Government funding and rely entirely on the Scottish public to raise the £4 million a year we need to help people with chest, heart and stroke illness throughout Scotland.

RESEARCH

We are one of Scotland's largest charitable funders of medical research, with a programme worth over £500,000 a year. We fund research projects throughout Scotland into all aspects of the prevention, diagnosis, treatment and social impact of chest, heart and stroke illness. If you would like more details, please call (0131) 225 6963 for an explanatory leaflet.

WELFARE

We provide small grants to people in financial difficulty because of chest, heart or stroke illness, for items ranging from clothing and bedding, to respite care. Applications are submitted through local Social Work Departments, or health professionals; for further information call (0131) 225 6963.

VOLUNTEER STROKE SERVICE (VSS)

We give practical help to people whose communication skills are impaired after a stroke. The VSS provides weekly group meetings and home visits for patients. For details ask for our VSS leaflet and Stroke Directory.

CHSS NURSES

Our nurses provide independent practical advice and support to those who have chest, heart and stroke illnesses, their families, carers and health professionals. There are dedicated nursing services in Fife, Glasgow, Grampian, Highland, Lanarkshire and Lothian. There is also a Scotland wide nurse led Advice Line (0845) 077 6000 calls are charged at a local call rate (out of hours answerphone). We have a wide range of booklets, factsheets and videos on chest, heart and stroke illnesses, which help towards an understanding of these conditions. Please ask for our publication list.

COMMUNITY SUPPORT NETWORK

CHSS provides support to affiliated chest, heart and stroke clubs through the Community Support Network. The clubs are independent and are run by local volunteers. The groups provide a range of activities and offer people support, stimulation and companionship in a friendly and relaxed environment. Please ask for the Group Directory for more information.

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INTRODUCTION

Stroke often happens out of the blue, without warning. People affected by stroke and their families are often left in shock and disbelief. Stroke can also cause a grief reaction due to the overwhelming sense of loss.

The aim of this booklet is to explain what a stroke is, what to expect in the recovery process and where to get help.

How to use this booklet

You will not be able to take in all this information at once!

This booklet takes you through the journey of recovery and is divided up in to small sections with an easy to use contents page. You can use this to find the information you want at the most appropriate time for you. Use this booklet along with the other booklets in the stroke series, as listed inside the back cover.

SECTION 1

WHAT IS A STROKE?

A stroke happens when the blood supply to part of the brain is disrupted in some way. As a result brain cells are deprived of the oxygen and nutrients which they need. Some brain cells become damaged and others die. The symptoms depend on the part of the brain affected and the extent of the damage incurred. This is why no two strokes are the same and why recovery is so variable.

Most strokes occur when a blood clot blocks one of the arteries which carries blood to the brain. This type of stroke is referred to as an ischaemic stroke since the term 'ischaemia' means an inadequate flow of blood.



A clot can block an artery (thrombosis).

However, some strokes are caused by bleeding within or around the brain from a burst blood vessel. This type of stroke is referred to as a haemorrhagic stroke, since haemorrhage is the medical term for the bleeding.



An artery can 'burst' and bleed (haemorrhage).

Ischaemic strokes

There are basically two different ways in which an ischaemic stroke can occur, cerebral thrombosis and cerebral embolism. In both cases the blood supply cannot continue past the point of blockage.

Cerebral thrombosis

You may hear your stroke referred to as a cerebral thrombosis. This means that a blood clot, known as a thrombus, has formed in an artery supplying blood to your brain and blocked the flow of blood. A thrombus quite

often forms where there is a damaged spot on the artery wall. The thrombus is more likely to block the flow of blood if the lining of the artery has become furred up with fatty deposits over the years. This furring up is known as 'atheroma' or 'atherosclerosis'.

Cerebral embolism

If your stroke is described as a cerebral embolism, this means it has been caused by an embolus. An embolus is a clot which formed elsewhere in your body and then travelled through your blood vessels to the brain, where it blocked an artery. The embolus may have formed in one of the blood vessels in your neck or it may have formed in your heart and then become dislodged. An embolus can form in the heart following a heart attack or be caused by an abnormal heart rhythm, or a problem with one of the valves of the heart.

Haemorrhagic strokes

There are two main types of haemorrhagic stroke.

Both refer to a bleed:

Intra-cerebral haemorrhage

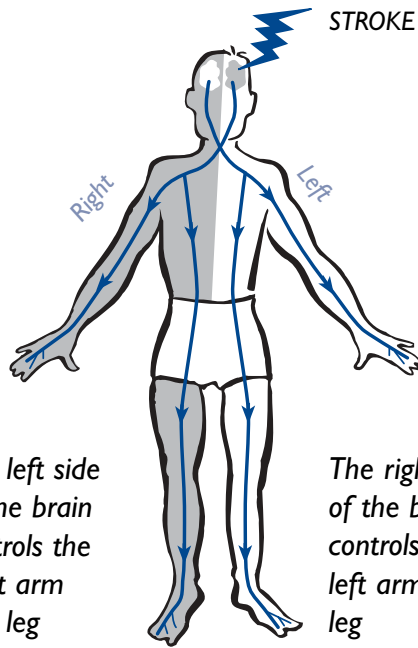
If your stroke is described as an intra-cerebral haemorrhage, this means that it was caused by bleeding inside the brain itself. The term intra-cerebral means within the brain.

Subarachnoid haemorrhage

Your stroke may be referred to as a subarachnoid haemorrhage. This means that it was caused by a blood vessel bursting and bleeding into the subarachnoid space, which surrounds the brain.

Right and left sides of the brain

The location of the stroke will dictate which side of the body is affected.



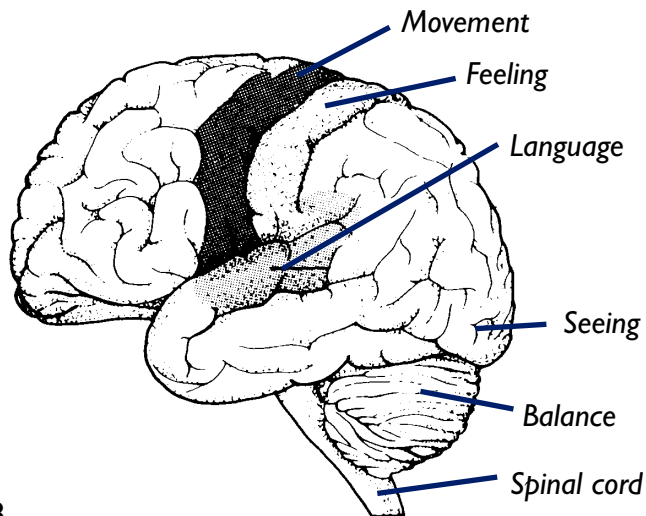
The left side of the brain controls the right arm and leg

The right side of the brain controls the left arm and leg

The left side of the brain controls the right side of the body and the right side controls the left side of the body.

Each side of the brain has different functions and this will dictate what affect the stroke has, or what symptoms the person experiences.

The left side of the brain normally controls reading, writing, speaking and understanding. So you are more likely to have speech problems if the stroke affects the right side of your body.



Movement, sensation and vision are controlled by both sides of the brain. Therefore these functions can be affected whichever side of the brain is damaged.

Effects of stroke

There are many different effects of stroke and you may only experience some of them. You or your family should ask your doctor for explanations of any symptoms that you find puzzling.

It is important to remember that no two strokes are the same, even if they are the same type of stroke.

How your stroke affects you depends on:

- which part of the brain was damaged
- how severe the stroke was
- your age and general health before the stroke.

The most common effects of stroke are:

- Weakness, clumsiness, heaviness or paralysis down one side. (This may affect an arm or a leg, one side of the face, or the whole of one side of the body).
- Swallowing difficulties.
- Disturbed vision.
- Loss of bladder / bowel control.
- Tiredness.
- Numbness / sensation problems.
- Balance upset, dizziness.
- Communication problems: written, spoken, reading, calculating.
- Psychological effects: mood swings, anxiety, depression.
- Cognitive effects: concentration and memory, the ability to process information.

Medical emergency

A stroke is a medical emergency and you should call for help immediately. If you think someone is having a stroke make sure the person is safe and call 999. It is important if the stroke was witnessed by someone that they should go to the hospital with the person, so that they can give an account of the symptoms and how they started. This is very helpful for the doctor to work out exactly what happened, especially if the person can not speak.

Diagnosis

It is most important to find out what caused the stroke. It is also important to stabilise your condition and prevent possible complications. For those not admitted to hospital an immediate referral to a stroke specialist and assessment clinic is desirable to ensure all necessary tests are carried out as soon as possible.

In the period after your stroke, it is likely that your doctors will want to perform some tests. These tests may be done for several reasons:

- To confirm that your symptoms were caused by a stroke and not by another condition that may give similar symptoms.
- To find out what type of stroke you have had, where it is and how severe it was.
- To monitor your condition and try to establish how you can best be helped to make the maximum possible recovery.
- To try to identify any possible causes for your stroke and reduce the risk of anything else occurring such as heart conditions, blood clotting problems, high blood pressure and diabetes.

Ask to speak to the doctor about your diagnosis and test results.

Tests and Investigations

The following are some of the tests which may be offered to you. It is unlikely for someone to need all these tests – your doctor will decide which ones are appropriate for you.

Blood tests

These can be used to check for certain conditions that may have contributed to your stroke, such as diabetes or problems with blood clotting.

Chest X-ray

This looks for underlying conditions such as heart or chest complaints that may have contributed to the stroke.



Electrocardiogram (ECG)

This test measures the rhythm and activity of your heart. Irregular heart rhythms can cause strokes and need to be treated.

CT (computed tomography) scan

This is a type of brain scan which identifies what kind of stroke you have had and the extent of damage the stroke may have caused. It is also used to exclude other types of illness that have similar symptoms to stroke. A scan should be done within 7 days of having a stroke and ideally within 48 hours.

Magnetic resonance imaging (MRI) scan

This is another type of brain scan which gives a more detailed picture than a CT scan.

Doppler or Duplex ultrasound scan

This is used to find out whether there has been a narrowing of the blood vessels in the neck (the carotid arteries), which supply blood to the brain. This narrowing can be a cause of stroke.

Echocardiogram (or cardiac ultrasound scan) this may be used to look for any heart problems that may have contributed to your stroke.

Drug treatment

There is currently no drug generally available, which can be given in the early stages of a stroke to protect the brain or to reverse any damage which has already occurred (although researchers are investigating the potential of several promising drugs).

‘Clot busting’ drugs can be used in some cases if it is clear that the stroke has been caused by a blood clot. However this treatment is not suitable for everyone and has to be used under special conditions.



Antiplatelets e.g. aspirin and anticoagulants e.g. warfarin can reduce the likelihood of further strokes in some people who have had a stroke caused by a clot.

Drugs may also be necessary to control other contributing factors such as high blood pressure, irregular heart rhythms, high cholesterol and diabetes.

Please refer to the booklet ‘Reducing the risk of stroke’ for more details.

Blood pressure monitoring

Your blood pressure will be monitored closely after your stroke.

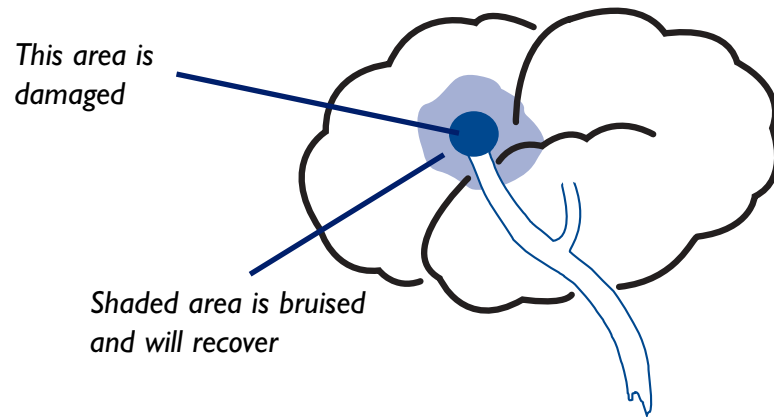
Most people have a rise in blood pressure after a stroke and this takes some time to get back to normal. However regular longer term monitoring is important to see how the blood pressure is under more usual conditions.

Please refer to the booklet ‘Living with High Blood Pressure’ for more details.



WHAT TO EXPECT

During a stroke some cells will die as a result of the loss of blood supply. Some will be damaged but recover and some cells will take over the role of ones that have lost their function.



The stroke causes swelling around the affected area and this interferes with the normal function of some cells. This swelling gradually settles down and the affected cells are able to recover their function.

However there is no way of predicting how a person will be affected long term. You have to wait for time to pass and allow this initial healing process to take place. Sometimes this feels like no-one is telling you what is going on but this is not the case it is just too early to know what the outcome will be.

This can take several weeks to months but during this time you may notice a lot of improvement in some of your symptoms or effects of stroke. When this improvement slows down it may be clearer what the long term effects of the stroke are going to be.

Tiredness

During the initial recovery period most people feel very tired (overwhelmingly so in some cases) and have difficulty concentrating and retaining information. The physical effects of stroke are often worse when overly tired as well so it is very important to try to get sufficient rest and not to overdo things. Instead it is best to try to find a happy medium of doing everything you need to do and getting enough rest.

What does recovery mean?

It might be unrealistic to expect everything to go back to exactly as it was before. The aim of recovery is to become as independent as possible within the limitations of the stroke. This is also known as rehabilitation.

Differences

Recovery depends on many different things and it is impossible to know how long someone's recovery is going to take:

- some people may make a complete or near complete recovery within weeks or months.
- about half may take months to years to gradually achieve near or complete recovery.
- less than a third will not make a full recovery.

Limitations

Therapy can only be tolerated for short periods of time and will only achieve a little at a time as the body becomes exhausted quickly. Tiredness after stroke makes it easy to become disheartened. Perseverance and endurance are needed to remain motivated during rehabilitation.

*You will need to
work towards
goals which are
realistic*

SECTION 2

EARLY DAYS

Where and when will treatment happen?

It is accepted that where possible it is best to go to hospital initially at least. It is difficult to be precise about how every stroke will be dealt with as there are so many variables.

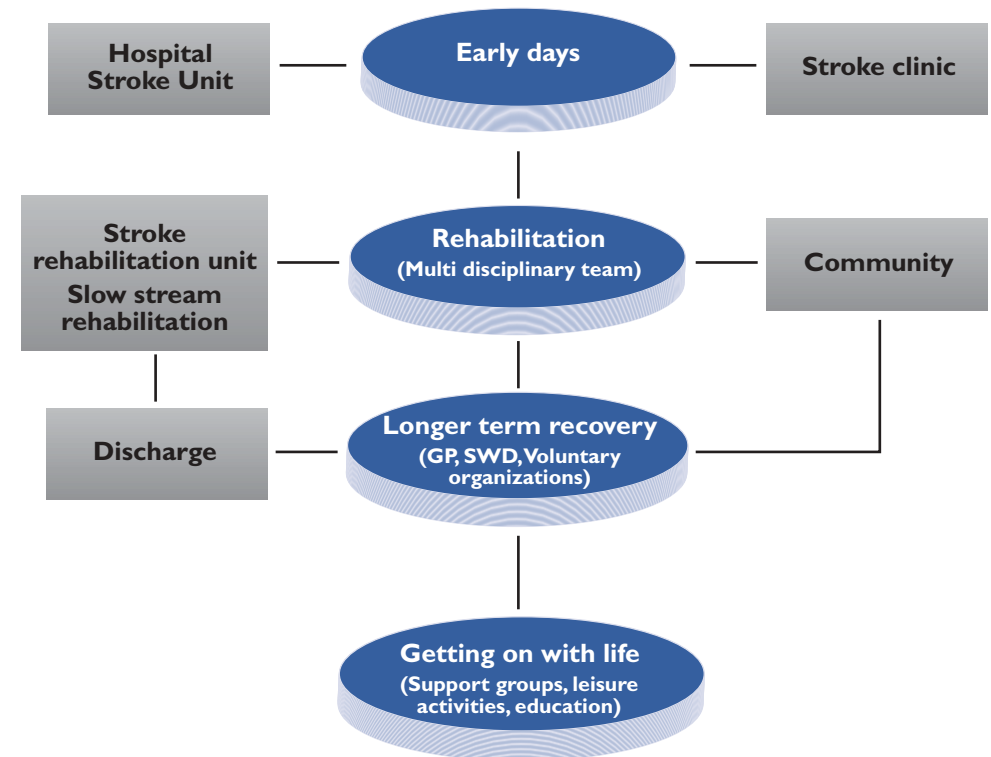
Research has shown that the best outcomes come from people being admitted to specialist stroke units but there are still limitations in some areas as to what care is available. This can also apply to services such as scanning and access to specialists.

The severity of the stroke determines how much looking after you will need, initially and longer term.

- Those with very disabling strokes, such as difficulty swallowing, poor conscious level and paralysis, will require more nursing care and therapy and need to be admitted to hospital. Problems with continence, skin care, constipation and pain, require monitoring and intervention to avoid complications.
- People with less severe strokes may be able to remain at home and have tests and investigations done at a local hospital clinic. Your GP can refer people to a stroke specialist and other therapies as required. Most hospitals now have special stroke clinics which allow people to be seen quickly without being admitted to hospital and have all the tests including a scan done in the same visit. A report can then be sent to the GP with advice on managing the care of the person.

In the longer term, rehabilitation can also be carried out in various ways such as admission to a stroke rehabilitation unit, out patient clinic or day hospital or by community therapists visiting at home.

THE STROKE RECOVERY JOURNEY



Taking care of personal needs

The nursing staff will provide help to ensure that all your needs are attended to, depending on how much you are able to do for yourself.

You may need help with everyday tasks such as getting washed and dressed, transferring from bed to chair, and going to the toilet.

In the first few days people who have had a stroke are likely to be:

- very tired and sleepy
- may find it hard to understand what is going on around them
- may find it difficult to remember information that has been given to them.

This is why it is important to have a family member around to fill in gaps and ask questions you may not feel able to. Write down a list of questions to remind you what you wanted to ask when you next see the doctor.



Communication problems

For those who have communication problems there are a host of other difficulties in making your wishes and feelings known and having your fears and worries addressed. Frustration is huge especially because of the suddenness of the onset. You may feel angry and cross or very emotional. You might even find other unplanned ways of expression come out such as swearing or singing. This is common and people will help and support you with this difficulty.

It is important for family to realise that difficulty in communicating is not the same as being confused. Careful assessment by a speech and language therapist is essential in identifying where the problems with language lie and explaining how to find ways of communicating.

The use of picture cards and boards can be helpful, as well as establishing at least a ‘yes’ and ‘no’ with the person affected. Thumbs up or down can easily be developed into a simple conversation.

Once a proper assessment is made the speech and language therapist can show you ways to work on improving communication difficulties.

Please refer to CHSS ‘Helping someone with communication problems’ fact sheet and ‘Picturing aphasia’ by Speakability. Or speak to the Adviceline nurses for more information.

Difficulty in swallowing

Some people have difficulty in swallowing after a stroke and this is why most people are not allowed to eat or drink straight away.

Once swallowing has been assessed it can be decided what form of eating and drinking is safe. Swallowing problems often improve quite quickly and thickened fluids, soft diet and then normal diet can follow. However it may be necessary to be given fluids by a drip (intravenous infusion) to avoid dehydration.

In some cases swallowing does not return or remains impaired and other methods have to be used to maintain nutrition such as tube feeding. In all these situations a speech and language therapist and the dietician are likely to be involved in your care.

Early mobilisation

It is very important to avoid prolonged time in bed even in the early days. This is called early mobilisation and has been identified as important for many reasons.

Early mobilisation:

- helps prevent the limbs becoming sore and stiff from lack of movement
- helps to recover sense of posture, balance and movement by being upright
- makes it easier to eat and drink
- reduces the risk of blood clots in the legs
- reduces the risk of developing a chest infection.

This is not to say that you will not need adequate rest. Most people after a stroke find they are overwhelmingly tired and want to sleep a lot. Ideally activity should be paced throughout the day, allowing rest and various therapy and activity periods to take place at different times of the day, not one after the other.

Avoiding damage

It is very important to listen to the advice of the physiotherapist and nurses about what will help movement to return and the positioning of affected arm or leg. Sometimes repetitive movements can cause spasm and damage.

Careful positioning is also vital in protecting the affected arm or leg from being damaged. Get advice and don’t rely on ‘old wives tales’.

Don't overuse the unaffected side

It is also important not to overuse your unaffected side. Encourage the damaged part of the brain to find alternative ways to make movement by trying to use the affected side as much as possible.

SECTION 3**REHABILITATION****Assessment is an on-going process**

Assessment is an on-going process that continues throughout your rehabilitation. Your progress will be monitored and, if necessary, the therapy you are receiving can be adjusted so that together you can work towards short term goals.

A care plan

Once you have been assessed it is likely that an individual care plan will be drawn up for you. This will set out the details of your rehabilitation and how the professionals involved intend to work towards them.

The care plan should be drawn up in consultation with you and your family.

Being realistic

The professionals involved in your care have to work towards long-term goals that are realistic for you. If they feel the goals that you have in mind are over ambitious, they might encourage you to set your sights a little lower or look at other ways to achieve what you want to do.

Your role

Remember that rehabilitation goes on 24 hours a day, even though you will spend much less time than that having sessions with a therapist. It is important that you do as much as you can throughout each day to put into practice anything you have learned during your therapy sessions. Nursing staff will help you with this process.

Your therapists may ask you to practice specific exercises or movements between sessions. Ask

how each exercise will help you achieve your long term goals such as walking and talking again. Understanding this will help keep you motivated. It may be easier to concentrate and to avoid tiredness if you practice your exercises for short periods several times a day rather than doing one long session. In spite of this there will be times when you find rehabilitation exhausting and you feel downhearted at slow progress. Try to remember that recovery after a stroke is often very gradual so you do need to persist.

Although your cooperation and determination are important factors in your rehabilitation you should not feel that you are to blame if you cannot make progress beyond a certain point. If your improvement does not continue in spite of your efforts these limitations are due to your stroke.



Doing as much as you can

Throughout your rehabilitation it is important for you to do as much for yourself as you can. This will boost your confidence and help your recovery. It can be difficult for those close to you not to step in and help with tasks like dressing or feeding yourself, which may seem unbearably slow at first. However your efforts will pay off in the long term with increased independence.

TEAM APPROACH

Rehabilitation after a stroke is best achieved by a team approach made up of the different professionals who will assist you with your recovery. This is often called the multi disciplinary team or MDT.

The team will work closely with you and your family and involve you in any decisions that are made about your rehabilitation.

MDT's are made up of various professionals including:

- Medical staff
- Nursing staff
- Physiotherapists
- Occupational therapists
- Speech and language therapists
- Dieticians
- Clinical psychologists
- Social workers (see section Getting help from the social work department)

An MDT works best by communicating regularly with each other at weekly meetings. This allows everyone the chance to share progress reports and to discuss any developments or problems that arise with anyone else who might be involved.

Medical staff

General Practitioner (GP)

Your GP will be in charge of your care if you remain at home. If you are admitted to hospital your GP will resume charge once you return

home. If you have any worries about the effects of your stroke, you should consult your GP who can refer you to other professionals and services.

Consultant

If you were admitted to hospital, you will be under the care of a consultant, a doctor specialising in a particular branch of medicine. The consultant usually works with a team of other fully-qualified but less senior doctors. What kind of consultant you are referred to may depend on your age, your type of stroke or the situation locally. You may be referred to a stroke physician, general physician, a geriatrician or a neurologist.

Nursing staff

Nurses provide nursing care and rehabilitation 24 hours a day. This close involvement provides valuable input to therapists involved in the care of the person affected and plays a major role in the recovery process.

Nurses can help with:

- building into your routine the advice received from therapists on how to manage daily activities like eating and drinking, washing, dressing and moving
- providing information, explanations and support to you and your family
- sorting out any problems, you should have a named nurse responsible for your individual care who you should talk to first of all.

Physiotherapists

Physiotherapists will provide an assessment of your movement and ability to balance. Early treatment will include guided movements of your limbs and correct positioning in bed or chair and transferring from bed to chair or to the toilet.

Physiotherapists can help with:

- using both sides of your body
- mobility
- treating shoulder pain
- preventing contractures (painful spasm in the arm or leg)
- preventing falls
- providing equipment such as splints, walking aids or wheelchairs
- adaptations to your home such as ramps or handrails to aid your mobility and independence at home.

Occupational Therapists

Occupational Therapists (often known as OT's) will initially do an assessment of what activities are physically difficult to carry out. The affect of a stroke on things like memory and concentration and the interpretation of what we see or hear around us can cause a variety of problems. This is also assessed. Depending on your specific difficulties, the OT can work out ways to deal with problem areas. Taking part in a range of activities, such as playing board games will have a specific purpose, although this may not always be immediately obvious to you.



Your OT will advise on aids and adaptations which will make it easier for you to manage at home

OT's can help with:

- everyday tasks like dressing, washing, eating, and possibly preparing simple food and drinks
- other practical daily activities such as shopping and managing money
- social activities that are important to you, such as gardening, painting, or getting out to see friends
- trying new hobbies
- developing skills you may need if you hope to return to work, either in your previous job or in a new career better suited to any limitations caused by your stroke
- adaptations to your home such as ramps or handrails to help your mobility and independence at home.

Speech and language therapists

Speech and language therapists see people who have difficulties with speaking, reading, writing and understanding speech or problems with swallowing. After doing a detailed assessment of communication difficulties the speech and language therapist can work out which techniques will be of particular help.

If your communication difficulties are likely to be long lasting, your speech and language therapist may help you find alternative ways of communicating. Depending on the effects of your stroke, this might be by using gestures or by using a communication aid or a computer. It is helpful to practise these new communication skills with your family and with the nurses who are caring for you.

If your stroke has caused swallowing difficulties, it means that there may be difficulty eating and drinking. Your speech and language therapist will carry out a thorough assessment to diagnose the exact problem and advise you and those caring for you on appropriate and safe ways for you to eat and drink.

Dieticians

Dieticians see people who have difficulties with their dietary needs or who have any problems with eating and drinking. They will oversee any special diet you require and advise on making sure you get all the nutrition you need.

Clinical psychologists

Clinical psychologists are often involved in helping and assessing people whose stroke has caused problems with thinking, learning, concentrating, remembering, making decisions, reasoning and planning. These are known as cognitive problems. Psychological problems such as depression or anxiety, or difficulties relating to other people may also be referred to a psychologist.

Asking for explanations

Whether you were admitted to hospital after your stroke or remained at home, you will find that a variety of professionals may be involved in your care. You will probably have a number of questions to ask.

It may help if you or someone in your family writes these questions down beforehand as it is all too easy to forget what you want to say during the discussion. It may also be useful if you or a relative can write down any important information you are given during the meeting

since it will be hard to remember everything that has been said.

Always ask professionals or anyone else who is helping you with problems concerning your stroke, to go over any points you are unclear about or to explain them in a simpler way.

If your stroke has caused difficulties in understanding what is being said, or if English is not your first language, make sure you have someone with you to help you communicate.

When ‘formal’ rehabilitation ends

The time will come when your ‘formal’ rehabilitation ends and you will no longer have therapy sessions with professionals. This does not mean the professionals concerned do not expect you to make any further recovery.

Progress does not necessarily stop just because therapy sessions have finished. Continue to set yourself realistic goals and work towards them by continuing to use the knowledge and skills which you have learned during your rehabilitation.

There is no fixed ration of rehabilitation that is right for everyone – how long your rehabilitation continues will depend on the problems you have and the progress you are making as well as the resources available in your area.

As time goes by after your stroke your situation may change. New problems may arise or old ones resurface. If this happens to you, you may ask your GP to refer you back to the appropriate therapist for a reassessment of your problem and for further treatment or advice.

LONGER TERM RECOVERY

Planning for discharge

If you have been in hospital it is a big step to think about going home. Although that is what most people want, there can be problems that need to be identified before it is possible to do so. It might be helpful to work out any particular skills you will need before going home. Plans need to be made so that as much is in place as possible for your return. This can be anything from aids or adaptations to the house, to arranging care or help to do the things you can not manage. To do this your home environment needs to be looked at to see how suitable it is for your return.

Home visit

A home visit is often arranged with either a physio or OT or both and you may be asked to go along.

The purpose is to have a look at where you live and assess how well you will be able to manage at home. It highlights problem areas such as any special equipment you might need, perhaps handrails to help you get up and down stairs or lowering kitchen work surfaces so that you can reach them from a wheelchair or adaptations for your bath or toilet seat.

The therapist will also check for safety such as loose carpets and other potential hazards. It is useful for any carer who is going to be helping you at home to be there for the visit. They can then be given some idea of what is planned and what their role will be. After this visit, your



hospital-based OT will send a report to OTs working for the local council's social work department, who are responsible for providing the aids and adaptations recommended for you.

Helping you prepare to go home

A short stay at home may be arranged before you are discharged. This can help identify any problems that may arise after you go home for good. It will also help you and your family to prepare for your homecoming.

After you go home, your OT may make follow-up visits to ensure you are using the aids and equipment correctly and that they are helping you. There may be a charge for some equipment or adaptations, depending on your means and the policy for charging in the area where you live.

Aids and adaptations

Aids are things like seating aids for bathing, or using the toilet, kitchen equipment and blocks to raise the height of chairs or beds.

Adaptations to the house itself may involve assessing your financial situation, (means testing), to see if you can contribute to the cost. This could be for sloping ramps for wheelchair access, rails and handles to help getting up stairs or steps and sometimes stair lifts.

The Disabled Living Centres Council has details of centres nearest to you where you can try things out before buying. (Contact details in useful addresses section.)

Even if you have to buy items yourself you may benefit from the advice of the OT on what is the best for you and where to obtain them.

There are also many companies that specialise in this sort of equipment and most do catalogues to let you see what they have. They often have shops displaying equipment for you to try. It is best to get advice and try things out before buying.

CHSS Adviceline can provide a list of useful company catalogues.

Wheelchairs are a special provision that is usually funded by the health service although more complex outdoor and motorised wheelchairs often have to be self funded. It is important that you are actually prescribed the correct chair and cushion for your particular needs. You and/or or your carer has to be able to use a wheelchair effectively. It also has to fit through the internal doors of your house and you have to have ramps and no steps to actually get out of the house. Special motors can now be bought that can be used with manual wheelchairs to make it easier to get around.



BENEFITS AND ALLOWANCES

The benefits system is complex, and changes frequently, so it is a good idea to get advice about what you are entitled to, and how to fill in claim forms. There are different benefits and allowances for people who are ill or disabled, for people who are carers and for people who are on low incomes. People on low incomes may also get housing benefit to help with the cost of rent, help with Council Tax and help with NHS costs such as travel to and from hospital.

Some benefits are taxed; some cancel each other out, some act as passports to other benefits.

Your benefits will be handled by your local Department for Work and Pensions formerly known as the Benefits Agency.

Independent Advice

The Citizens Advice Bureau knows their way round the benefit system and can give you independent advice if you are trying to work out what you should claim for. Your local council office can give you details about any local welfare or benefits advice shops that you can visit or phone.

BEING HOME

Many services now have a stroke liaison nurse or stroke nurse who as well as seeing you in hospital can help with the transition from hospital to home and continue to visit after discharge to help with any subsequent problems.

Many people find that once back into their 'normal' environment, problems make themselves apparent that were not really a difficulty in hospital.

The ward can be quite a protective environment with people on hand to ask for help or information. In particular this relates to visual problems*, cognitive difficulties* and incontinence. General hustle and bustle can be very distracting, making things like going to the supermarket, into town or being in a crowd, unexpectedly daunting and uncomfortable.

It is very important to get as much information as possible about how to get help and who to ask once you have left the hospital, before you go home.

(*Please see stroke series list for more information on these topics.)



BACK TO WORK?

The effect of stroke on younger people can be even more traumatic and devastating because as well as the losses the stroke has caused physically there is also a huge impact on a working person's life in terms of earning a living and their role within society and the family.



Some people can be unrealistic about returning to work and take on too much too soon. Tiredness, cognitive problems such as memory loss and difficulty concentrating can cause as many hurdles in the work place as physical disability. Your old job may not suit you any more. It is very important that you speak frankly to your employer so that you do not put yourself under too much pressure to perform. Working reduced hours and

with a reduced workload is sensible as you may find being very over tired makes things more difficult. Working every day might be too much to begin with. Give yourself a chance and don't be too hard on yourself if things don't work out the way you want them to.

Many people do make a success of returning to work. Many see it as an opportunity to try something else, work from home, and take up new challenges.

See a Disability Employment Advisor at your local job centre. They will be able to give you advice about careers and retraining. They can also put you in touch with organisations that specifically provide opportunities for people with disabilities.

GETTING HELP FROM THE SOCIAL WORK DEPARTMENT

Assessment of your needs

In order to receive support services, you will first need an assessment from social work. People with disabilities have a right to an assessment under Section 4 of the Disabled Person's (Services, Consultation and Representation) Act 1986.

How an assessment is arranged

If you were admitted to hospital following your stroke, the hospital social worker may arrange for an assessment. If this does not happen, or if you are being cared for at home, you can contact social work direct to ask for an assessment or ask your GP to do so for you.

Assessment of your carer's needs

If you have a carer, he or she also has the right to an assessment of needs under the Carers (Recognition and Services) Act 1995. However, although some social work departments have carer support teams which offer support specifically to carers, they are not obliged to offer services to carers.

Financial assessment

Social work can charge for support services. Any assessment of your needs will include an assessment of your financial situation to find out how much, if anything, you can afford to pay. The amounts charged for services will vary from area to area but they should be reasonable and take into account your ability to pay.

Services

The person carrying out your assessment may ask other people to visit you and may discuss your situation with colleagues. If it is clear you are in need of particular services, social work should ensure these are provided. Social work should review your situation from time to time to take account of any changes in your needs. However, if there has been a change in your situation and you need more or different kinds of help, don't wait for a review. Get in touch with your local social work department immediately.

Residential and nursing home care

If your stroke was quite severe and left you with lasting problems, you, your family and your doctor may feel that you need residential or nursing home care. A residential home provides personal care and meals while a nursing home must have qualified nurses on the premises and is able to offer more intensive support. Some people are eligible for financial help towards the cost of nursing and personal care while in a nursing home.

SECTION 5

THOUGHTS AND FEELINGS

You are likely to feel very anxious or upset in the weeks and months following your stroke. This is quite normal, particularly if your recovery is slow or uncertain. You may be angry about what has happened to you, frustrated that you can no longer do what you did before, or frightened by lapses in your memory or difficulties in communication. You may grieve for the loss of abilities you once took for granted and wonder if you will ever regain them. You might feel scared that another stroke will happen. Sometimes the effects of your stroke may make you more irritable or demanding. You may also find that you are affected by mood swings, which can make it even more difficult for you and your family to cope.

Some people experience something called 'emotionalism' as a result of their stroke. This has the effect of extremely emotional reactions that are out of context or proportion. For example laughing or giggling inappropriately or crying for no apparent reason.

Affect on the whole family

Others in your family may also be experiencing some very upsetting feelings. Like you, they may be anxious about your situation and grieving for the way it has affected both your life and theirs. They may also sometimes feel resentful about the changes they have had to make because of your stroke or about the demands of caring for you and they may experience guilt at having these feelings.

Sharing your worries

Feelings are often much easier to handle if you share them. You and your family may find that it helps to be more open with each other about your worries. However, you may find it difficult to discuss painful feelings with those who are closest to you. If this is the case then you should each try to find someone outside the family who will listen and understand. It might be a health professional, a good friend, counselling services, a support worker for CHSS or another voluntary agency.

Seeing friends

You may feel embarrassed about the effects of your stroke and this may make you feel tempted to restrict your social life and cut yourself off from the outside world. But doing this will only make things harder in the long run, both for you and for your partner or family. Encourage friends to visit (for short periods if you get tired) and accept any suggestions to go out on manageable trips. The more you see people and the more you get out, the easier it will become.

Depression

Feeling down for some of the time is a very natural reaction after a stroke. However, if you are feeling very low for most of the time you could be depressed. Sometimes people do not realise how depressed they are especially when they have been feeling the same for a long time, or if they have more physical symptoms than emotional. Some symptoms of depression could be a direct result of your stroke and it can be difficult to decide what is caused by what. This is all the more reason to get some advice.

Common symptoms to stroke and /or depression are:

- tiredness and loss of energy
- loss of confidence and self esteem
- difficulty concentrating
- not being able to enjoy things that are usually pleasurable or interesting
- undue feelings of guilt or worthlessness

Other symptoms of depression include:

- persistent sadness, crying spells
- loss of interest in life
- mood swings, grumpiness or being easily upset
- changes in appetite / weight gain or loss
- feelings of helplessness and hopelessness
- sleeping problems- difficulties in getting off to sleep or waking up much earlier than usual
- lack of energy, motivation
- being less aware of others and more inward looking
- physical aches and pains
- loss of sex drive and or sexual problems
- avoiding other people sometimes even your close friends
- thinking about suicide and death.



If depression takes hold, it will make it harder for you and your family to cope. As discussed earlier, your recovery depends to a large extent on your input. If you are depressed it will be hard to motivate yourself to keep working on your recovery. Depression makes you feel lethargic and that there is no point in doing anything or seeing anyone. This booklet will have shown you how there are things that will help you recover from your stroke. There are very successful drug treatments for people with depression. Antidepressant drugs balance the chemicals in the brain responsible for these feelings. There are different types used depending on your personal symptoms and medical history and they are not addictive. However you must let someone know about how you feel. The sooner depression is addressed the quicker it can be helped. Your GP may suggest antidepressant medication or may arrange for you to have counselling or other support.

THE FUTURE

It is important for you and your family to find ways of getting the most out of life after your stroke. In the first few months you may be concentrating on relearning old skills or acquiring new ones. However, once you know how much recovery is likely, you will need to come to terms with the restrictions imposed by your stroke. You can then try to find ways around them to enable you to enjoy life as much as possible.

What else you can do to help yourself

Try to be positive. Think in terms of what you have, rather than terms of what you have lost.

How to improve your general health:

- stop smoking.
- know and control your cholesterol.
- know and control high blood pressure.
- take your medication as prescribed.
- control diabetes.
- keep as active as you can within your abilities.



CHSS has a variety of booklets and fact sheets with all the information you will need on these subjects

HELP FROM CHEST HEART AND STROKE SCOTLAND (CHSS)

Community Services provide groups and clubs to meet the varying needs of people who have had a stroke.

Volunteer Stroke Service (VSS) The aim of the VSS is to support people who have had a stroke, particularly those left with communication problems. The VSS offers weekly stroke groups, including groups specifically for younger people, home visits, a hospital visiting service and carers support.

Community Support Network (CSN)

The aim of the CSN is to support local volunteer led groups, which provide social support and activities for people affected by chest, heart or stroke illness.

Information

A full range of booklets and fact sheets are available by contacting the Publications Department at Head Office by telephone or by email: publications@chss.org.uk or via the CHSS website www.chss.org.uk or by Fax : 0131 220 6313

CHSS Advice Line: 0845 077 6000

The advice line is staffed by nurses and provides confidential, independent advice on all aspects of stroke illness to those people affected, their families, carers and health professionals. All calls are charged at the local rate. Out of hours answer machine. Monday – Friday 9.30-12.30 and 1.30 – 4.00.



CHSS Stroke Nurses

CHSS provides dedicated services in Fife, Grampian, Highland, Lanarkshire and Lothian, facilitating a smooth transition from hospital back into the community for people who have had a stroke and their families.

Other Services

CHSS also provide welfare grants, and funds research into stroke.

Phone Head Office on 0131 225 6963 for further information on any of these services or look at the website www.chss.org.uk

USEFUL ADDRESSES

Age Concern Scotland

Leonard Small House
113 Rose Street
Edinburgh EH2 3DT
Tel: 0131 220 3345
Fax: 0131 220 2779
Email: enquiries@acscot.org.uk
Information Line: 0800 009 996

Age Concern Scotland offers advice and information to older people. Some areas provide such services as day care or home care.

Help the Aged

11 Granton Square
Edinburgh EH5 1HX
Tel: 0131 551 6331
Fax: 0131 551 5415
Email: infoscotland@helptheaged.org.uk
Seniorline 0808 800 6565
Textphone: 0800 269 626

Provides support for older people including advice, information, grants and advocacy. Seniorline telephone advice service also available.

British Red Cross-Scotland

Alexander House
204 Bath Street,
Glasgow G2 4HL
Tel: 0141 332 9591
Fax: 0141 332 8493
Website: www.redcross.org.uk

Have local branches which can lend or hire equipment for people with disabilities. They also can help with transport and first aid training.

RNIB Scotland

Royal National Institute for the Blind
Dunedin House
25 Ravelston Terrace
Edinburgh EH4 3TP
Tel: 0131 311 8500
Email: rnibscotland@rnib.org.uk
Website: www.rnib.org.uk

Provides a wide range of specialised information and services for partially sighted and blind people.

Visibility

2 Queens Crescent, Glasgow G4 9BW
Tel: 0141 332 4632
Fax: 0141 353 2981
Website: www.visibility.org.uk

Visibility is the new name for Glasgow and West of Scotland Society for the blind. The charity provides a range of services and activities for people who are visually impaired.

Princess Royal Trust for Carers

(Glasgow Office)
Campbell House
215 West Campbell Street
Glasgow G2 4TT
Tel: 0141 221 5066
Fax: 0141 221 4623
Email: infoscotland@carers.org
Website: www.carers.org

Provide advice and support to carers on all topics and providing information about what services are available locally. Centres all over Scotland but will put you in touch with another carer organisation if necessary.

Carers National Association Scotland

91 Mitchell Street
 Glasgow G1 3LN
 Tel: 0141 221 9141
 Email: info@carerscotland.demon.co.uk
 Careline: 0808 808 7777

Provides advice and encouragement for carers and provides training for health professionals and carers as well as campaigning for awareness.

The Continence Foundation

307 Hatton Square
 16 Baldwins Gardens
 London EC1N 7RG
 Email: continence-help@pipex.com
 Helpline 0845 345 0165
 Website: www.continence-foundation.org.uk

National organisation which provides personal and confidential advice from specialist nurses for people with bladder and bowel problems. They can also put you in touch with your local continence advisor.

Diabetes UK Scotland

Savoy House
 140 Sauchiehall Street,
 Glasgow
 G2 3DH
 Tel: 0141 332 2700
 Fax: 0141 332 4880
 Email: Scotland@diabetes.org.uk
 Website: www.diabetes.org.uk
 Careline: 0207 424 1030

Provides support and information for diabetics and their families and supports diabetic research.

Depression Alliance Scotland

3 Grosvenor Gardens, Edinburgh EH12 5JU
 Tel: 0131 467 3050
 Fax: 0131 467 7701
 Website: www.depressionalliance.org.uk
 Email: ruthl@depressionalliance.org.uk

Provides information, support and understanding to those affected by depression. Campaigns to raise awareness amongst the general public about the realities of the condition.

Different Strokes

9 Canon Harnett Court
 Wolverton Mill, Milton Keynes MK12 5NF
 Strokeline: 0845 130 7172
 Fax: 01908 313 501
 Email: info@differentstrokes.co.uk
 Website: www.differentstrokes.co.uk

Different Strokes is a national charity set up by young stroke survivors for young stroke survivors. It provides information, support and exercise opportunities, a telephone service and counselling.

Disabled Living Centres Council

Redbank House
 4 St Chad's Street
 Cheetham Manchester M8 8QA
 Tel: 0161 834 1044
 Fax: 0161 839 0802
 Textphone: 0161 839 0885
 Email: dlcc@dlcc.org.uk
 Website: www.dlcc.org.uk

Disabled Living Centres offer information, advice and exhibitions of products and equipment for people with disabilities. Phone for details of your nearest centre.

Disabled Living Foundation

380-384 Harrow Road

London

W9 2HU

Helpline: 0845 130 9177

Textphone: 0207432 8009

Email: advice@dlf.org.uk

Website: www.dlf.org.uk

Disabled Living Foundation has become the leading source of information and advice on products, equipment and technology for people with disabilities. Specialist training and comprehensive databases provide solutions to problems that limit an individual's independence.

Epilepsy Scotland

48 Govan Road

Glasgow

G51 1JL

Tel: 0141 427 4911

Fax: 0141 419 1709

Helpline 0141 427 5225

Email: enquiries@epilepsyscotland.org.uk

Website: www.epilepsyscotland.org.uk

Provides information, counselling, support and advice.

NHS 24

Tel: 0845 424 24 24

Website: nhs24.com

Nurses provide advice about symptoms and seeking medical attention. Operating in Grampian, Highland, Greater Glasgow and Ayrshire and Arran and Fife.

NHS Helpline 0800 22 44 88 links in with NHS 24 in areas where this is available.

Also provide information about patients' rights, self help and support groups, waiting times and NHS dental care.

PINNT

(Patients on intravenous and naso-gastric nutrition therapy)

Scottish contact:

Mrs Sharon Bell

59 Loanfoot Avenue

Knightswood

Glasgow G13 3DG

Tel: 0141 959 6701

This is a charity that offers support for people receiving parenteral or enteral nutrition therapy. It also aims to promote awareness and understanding and works in conjunction with health professionals to improve life at home. They offer written advice and information about many aspects of life with nutritional therapy, a newsletter and local support groups.

Speakability

1 Royal Street

London SE1 7LL

Tel: 0207 261 9572

Fax: 0207 928 9542

Helpline: 0808 808 9572

Website: www.speakability.org.uk

Speakability is a national charity that supports people living with aphasia and their carers through its information service, network of groups, activities programme and range of booklets.

Relationships

Couple Counselling Scotland

18 York Place
 Edinburgh EH1 3EP
 Tel: 0131 558 9669

This is the umbrella organisation that covers the whole of Scotland and will provide information about couple counselling in your area. They can also find more specialised services such as psychosexual counselling.

SPOD - Association to aid the sexual and personal relationships of people with a disability is no longer running.

However similar leaflets and a helpline are still available through another organisation called Outsiders:

Sex and Disability Helpline
 Tel: 0707 499 3527
 Weekdays 11am – 7pm
 E-mail: outsiders@clara.co.uk
 www.outsiders.org.uk

STROKE PUBLICATIONS

Booklets

- SS1 Stroke a guide to your recovery
- SS2 Stroke: a carers guide
- SS3 Reducing the risk of stroke
- SS4 I've had a stroke: Essential information on admission to hospital
- SS5 Understanding TIA's
- SS6 Sex after stroke illness
- H4 Living with High Blood Pressure

Video - Stroke Matters: £30.00

Resource pack comprising two videos and two booklets (This video can be hired as well as bought.)
 Booklets are available separately: Making sense of stroke and Facing the future.

Factsheets

- F1 TB: Information about tuberculosis
- F2 Salt
- F3 Cholesterol
- F4 Warfarin
- F5 Helping someone with language problems
- F6 Holidays
- F7 Insurance companies
- F8 Suggested book list
- F9 Driving after a stroke
- F10 10 common questions asked after a stroke
- F11 Mouthcare after a stroke
- F12 BCG - Protection against tuberculosis
- F13 Air travel for people affected by chest, heart and stroke illness
- F14 Eye problems after stroke
- F15 Memory problems after stroke

A full publication list is available from Head Office.

**65 North Castle Street, Edinburgh EH2 3LT
 Telephone: 0131 225 6963**

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