



STROKE SERIES SS7

STROKE IN YOUNGER PEOPLE

100 YEARS OF CARING

CHEST, HEART
& STROKE

SCOTLAND



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 £5 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 £600,000 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.

PERSONAL SUPPORT GRANTS

We provide small grants to people in financial difficulty, because of chest, heart or stroke illness, for items ranging from disability equipment and household goods to respite care and holidays. Applications are submitted through local Social Work Departments, or health professionals.

VOLUNTEER STROKE SERVICE (VSS)

We give support to people whose communication skills are impaired after a stroke. The VSS provides weekly group meetings and home visits for patients.

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, Grampian, Highland, Lanarkshire, Lothian and Dumfries and Galloway. 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.

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 more information.

FOR FURTHER INFORMATION ABOUT ANY OF THE SERVICES ABOVE PLEASE CONTACT HEAD OFFICE BY PHONING 0131 225 6963 OR VISIT THE CHSS WEBSITE: www.chss.org.uk

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Our thanks go to everyone involved in the making of this booklet, for their support, contributions and expertise. Special thanks go to:

Members of PALS CHSS Young Stroke Group
Lanarkshire

Anne Armstrong CHSS Young Stroke Support Worker
and her clients

Dr Pauline Banks

Teresa MacIntosh

INTRODUCTION

This booklet is designed to be used along with another CHSS booklet called Stroke: a guide to your recovery. Detailed information about what a stroke is and recovery from stroke can be found there. However the aim of this booklet is to address some of the common issues that affect younger people who have had a stroke.

This booklet does not address stroke in childhood. 'Care after stroke in childhood' is an information booklet available from the Royal College of Physicians London, for parents and families of children affected by stroke. It is available from their website www.rcplondon.ac.uk

Stroke is often considered an illness of old age, but many young people are affected by stroke too. Studies exploring the experiences of younger people affected by stroke and their families have identified common issues. One of the most frequent feelings is people wish to be treated as individuals, and services in hospitals and communities need to be tailored to aid recovery and rehabilitation. The affects of stroke can put pressure on relationships with a partner and within the family. Stroke can also cause difficulties with other responsibilities such as caring for children or going back to work. These issues are explored more within this booklet. If you need further help speak to your stroke nurse or contact the CHSS Advice Line.

WHAT HAPPENED TO ME?

Retention of information has been found to be poor in the initial stages of an acute illness including stroke. So it is important to receive information throughout the recovery period. You may find you have blanks in your memory but don't be afraid to ask what happened or you may worry unnecessarily. You may have already been given the answers, but there is nothing wrong with asking for information again if you can't remember.

You are 'normal'

Researchers have found that there are many common questions, issues and challenges facing all younger people who have had a stroke irrespective of their degree of physical disability. Obviously every individual will have a different and unique experience but it is very important to recognise that you are not alone and that most of what you are experiencing is quite 'normal'.

Your journey

Your journey of recovery from stroke involves various stages of realising the things that have changed because of the stroke and then readjusting to the effects these changes have on your life. Not all the changes will be obvious in the early recovery period. Coping with the hidden difficulties that can arise from changes to thinking, such as memory and understanding, psychological and emotional problems can be a real challenge. The journey can be lengthy and progress needs to be monitored and re-assessed regularly.

Avoiding comparisons

You may find yourself comparing your recovery against that of other people who have had a stroke. However it is very important to accept that no two strokes are the same. Every individual will experience differing degrees of severity and speed of recovery, and people with similar problems will react differently.



COMING TO TERMS WITH STROKE

Why me?

Coming to terms with having a stroke is something that many younger people have difficulty with. You may have never been ill previously or have any risk factors for stroke. You certainly did not expect something so devastating to happen to you. It is normal to expect things to be put right or be reversible but the damage done by stroke may have to be lived with for a long time. After more severe strokes the transition into 'disability' may be very difficult to deal with. With less severe strokes invisible problems such as difficulty concentrating, tiredness and negative feelings about your body image can cause frustration and upset. As part of your recovery you may find yourself questioning many aspects of your life such as what the future holds, your spiritual beliefs, your role in society, your relationships with others and your ability to work.

Grief reaction

A stroke may present many losses. Physical and psychological abilities may have changed as may your level of independence and hopes for the future. Changes in your family and social relationships can also leave you with feelings of loss. Dealing with these potential changes can feel like a grieving process and often people who have had a stroke say they feel like part of them has died.

In younger people this reaction and the anger and frustration involved can feel overwhelming, as can feelings of guilt they feel for the effect of their stroke on their family and friends.

The different stages of grief reaction you may experience.

<i>Shock and disbelief</i>	A feeling that what is happening is not real, that you will wake up and all will be well again.
<i>Denial</i>	A refusal to accept the consequences of what has happened. This can last for days or months and sometimes longer. Denial protects you from being overwhelmed by the change in your life. Unfortunately some people get stuck in denial and never feel they have come to terms with the effects of their stroke.
<i>Anger</i>	Anger is a normal emotional response, as the full implications of what has happened to you are realised. You may feel angry with yourself, with God, with the doctors and nurses for not doing enough for you. Anger is often directed at the person closest to you, which can cause feelings of being misunderstood for both of you. The full implications of what has happened are realised.
<i>Loss</i>	Many feelings of loss may be experienced as you adjust to having a stroke and look back to how life was before the stroke.
<i>Anxiety</i>	Anxiety after a stroke is often related to feelings of fear. Fear of dying, fear of having another stroke, fear of the unknown, fear of losing your identity and fears about your roles and responsibilities.
<i>Guilt</i>	Guilt can be about what caused the stroke, about the disruption and worry to the lives of those around you, about not being able to work, about not being able to contribute as before. Feelings of guilt can be powerful and destructive and can be completely irrational.
<i>Acceptance and adjustment</i>	Adjusting to the way things are for you after your stroke is a gradual process that happens over a long period of time.

See the CHSS booklet 'Coming to terms with Stroke' for more information.

WILL IT HAPPEN AGAIN?

Much depends on the cause and type of stroke especially whether it was a bleed or a blockage. Tests are necessary to find out as much as possible about this. These might include testing the blood for various things, measuring blood flow through blood vessels, checking the heart to look for any abnormalities. An inherited or genetic condition could have caused a disorder in the clotting mechanism of the blood. Some strokes in younger people are caused by bleeding from a weakness or malformation in a blood vessel that may have been present since birth.

Doctors can't always find a reason

Unfortunately no explanation can be found for some strokes. If this is the case you have to try and accept the fact that you may never get answers to your questions. You must concentrate on being positive, reduce any known risk factors as much as possible and be vigilant in monitoring your health.

In some cases it may be possible to consider surgery to prevent further stroke. Blood thinning medication may be considered as a preventative measure. The risk of another stroke lessens as time passes.

Making lifestyle changes

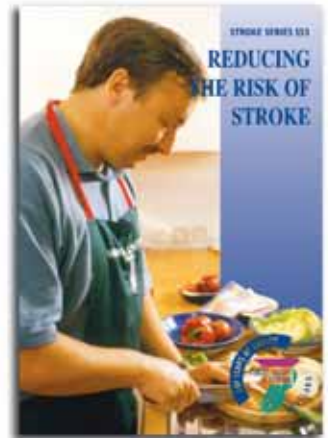
It can be a big challenge to change lifestyle habits such as smoking and drinking, or serious problems such as substance use. Knowing that these changes will reduce your risk of another stroke doesn't mean they are easy to make. You may feel that the stroke has affected your choices in life too much already, and you may feel resentment about making healthy changes to

your lifestyle. A compromise of cutting down if unable to cut out will help to ease conflict if it arises. Some people will take longer than others to come to terms with their stroke and so resist changing their lifestyle.

What you can do to help yourself

There are several well understood medical conditions that are underlying causes of stroke: *High blood pressure, High cholesterol, Diabetes, Atrial fibrillation*. The following measures are known to improve some or all of the conditions mentioned as well as reducing the risk of stroke. So taking steps to implement these changes **will** be a worthwhile investment.

- Stop smoking.
- Enjoy a varied, low fat and reduced salt diet, including 5 portions of fruit and vegetables a day.
- Control your weight for your age and height.
- Keep as active as possible.
- Moderate alcohol intake – binge drinking is particularly dangerous as it raises blood pressure.
- Avoid recreational drugs. Amphetamines, cocaine and ecstasy increase the risk of stroke.
- The combined oral contraceptive pill may make the blood more likely to clot, especially in women with other risk factors, and may also raise blood pressure. You may want to discuss other forms of contraception with your doctor.



See the CHSS booklet 'Reducing the Risk of Stroke' for more information.

HIDDEN DISABILITIES

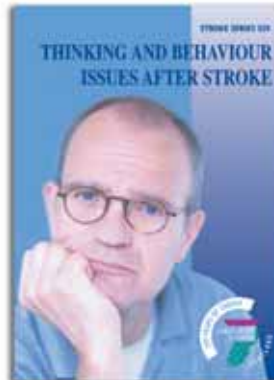
Many of the strokes experienced by younger people are categorised as ‘minor’ strokes and the outcome is usually a good recovery. However there are often symptoms or problems with these strokes that are less obvious than the physical ones, such as loss of power in a limb or communication problems.

Thinking (cognitive) problems

Many people experience ‘thinking’ problems such as poor memory and difficulty concentrating and this can be very distressing and frustrating for you and for those nearest to you. These difficulties often improve quite quickly and may well resolve in the first 1-3 months, for others it can take longer. It takes time and patience to adjust to these problems often referred to as cognitive problems.

There are some cognitive problems that are caused because a specific area of the brain has been damaged, and these may affect your mental abilities and problem solving skills longer term.

See the CHSS booklet ‘Thinking and behaviour issues after stroke’ for more information.





Emotional and behaviour problems

There are some features such as boredom, frustration with the slowness of recovery, altered marital and family relationships, and anxiety about the future which are completely normal and understandable after having a stroke. You may find that even small failures can trigger intense frustration, despondency or anger, which may spill out in an emotional outburst. This can be alarming for your family who may find it hard to understand your frustration, especially if they feel you are progressing well.

How people react to their circumstances is unpredictable and varies enormously. Mood changes, grumpiness or bad temper, losing patience easily, over reacting to children's noise and their needs for attention are all frequently experienced. Unfortunately some people who have had a stroke don't realise the effect this has on those around them. These problems can lead to disharmony within families and relationships. Talking about how you all feel can help.

Tiredness after stroke

It is quite common for people to be very sleepy for much of the time immediately after a stroke but this usually passes in the first few months. Many people experience a different tiredness, a profound fatigue that can go on for weeks, months and sometimes as much as a year or two after the stroke.

Often symptoms from stroke are exacerbated by tiredness making them temporarily worse. This especially affects things such as speech, concentration and memory.



As there is a tendency to overdo it on better days the result is feeling twice as tired the next day. This can add to feelings of frustration with your overall impression of your progress.

Therapy can be exhausting and so for some people doing a little and often, is more effective than trying to do too much at one time. This does not mean there will not still be progress. It may just not be as quick as you would like it to be.

Recognising that tiredness is a real problem after a stroke can help you find ways to overcome practical problems, such as by pacing yourself. This will enable you to participate as much as you are able to, and can give you a feeling of having more control in your life.

There are strategies that can help:

- There is a tendency to overdo it on a good day and be overly tired the following day. This is why you must pace what you do, no matter how well you feel.
- Set yourself realistic goals for each day. Plan important things for times when you will be most rested.
- Divide big jobs into smaller pieces.
- Build rest periods into your day.
- Do not be afraid to ask for help. It is important to conserve your energy for those things that are important to you and your ongoing recovery.
- Know your limitations. Don't feel judged or be put off by other people's expectations of what you should or shouldn't be doing. Remember this is about you and your body – get to know when it is time to stop and stick to it.
- Continue an exercise regime when you are discharged from physiotherapy. Exercise is known to be effective in fighting fatigue and helps to lift your mood. Do exercises at home and find out if there are any appropriate keep fit classes in your area.

See the CHSS factsheet 'F18 Coping with tiredness' for more information.

Depression

Feeling down for some of the time may be a natural reaction after a stroke. However, if you are feeling low for most of the time you could be depressed. Some people feel there is a stigma attached to being depressed or are afraid of what other people will think of them.

Sometimes people do not realise they are depressed especially when they have been feeling the same for a long time.

How can depression affect your recovery from stroke?

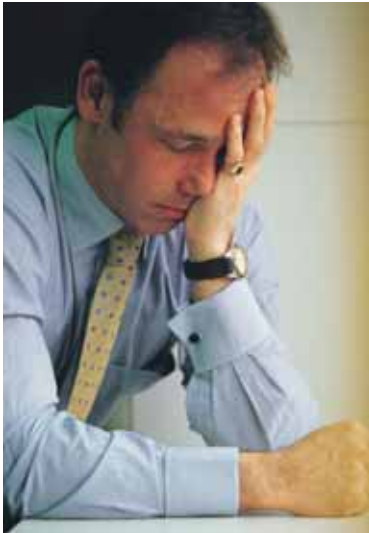
Most people find they have good and bad days and this is true of having a stroke and of depression. Your physical recovery from stroke depends to a large extent on your input. If you are depressed it will be harder to keep motivated to work on your recovery and rehabilitation. Depression makes you feel lethargic and that there is no point in doing

anything or seeing anyone.

This can contribute to feelings of isolation and loneliness that can bring you to a halt.

When can depression set in?

There is no definite time that you may suffer from depression; it can develop soon after having a stroke or months afterwards. Depression is very common and doctors are very familiar with it and how to treat it.



Symptoms of depression

Some symptoms may be present as a result of your stroke such as tiredness, memory problems, difficulty concentrating, loss of self esteem etc. Other symptoms may be as a result of the emotional difficulty involved in coming to terms with having a stroke but these should not cloud the possibility that you may be depressed and benefit from treatment.

Most experts agree that if you have experienced four or more of the symptoms below for most of the day, nearly every day, for over two weeks then you should seek help.

Speak to your doctor in the first instance.

- tiredness and loss of energy
- loss of confidence and self esteem
- sleeping problems – disrupted sleep pattern
- persistent sadness – tearful/crying
- avoiding other people even close friends
- feeling irritable
- difficulty concentrating
- difficulty making decisions
- not being able to enjoy things that are usually pleasurable or interesting
- feeling pessimistic
- feelings of guilt or worthlessness
- feelings of helplessness and hopelessness
- lack of interest in sex

- physical aches and pains / constant headaches
- thinking about suicide and death
- self harming

Treating depression

There are some things your doctor can help you with, therapies and organisations that you can seek help from and things you can do yourself. Most people say that just recognising that there is a problem can be helpful right away.

Here is a summary of treatment and self help to consider:

- talk about it
- antidepressants
- talking therapies
- support groups
- physical activity
- relaxation techniques
- good diet
- improve sleep

See the CHSS booklet 'Coming to terms with stroke' for more information.

RESUMING A SOCIAL LIFE

Social Life

After a stroke some people find social situations overwhelmingly difficult, especially if they have communication difficulties or find the mental stimulus of crowded and noisy places uncomfortable.

As you come to terms with the effects of your stroke you may feel that associations with people and places from your life before you had your stroke are painful and remind you of what has changed. You might avoid friends and acquaintances fearing they might ask questions about your stroke or feel sorry for you. This will improve in time and by letting others understand, accept and support you, you will start to feel more positive.

You may experience practical difficulties in going to places you went before, and you may have fears of not managing when out. It may seem easier to stay at home in your safe comfort zone – but this leads to isolation and worsens your fears. There is always a way and you are still you!

Even though you may be relying on other people to understand and co-operate, don't be disheartened before you try. Fear of the unknown is a very powerful emotion but if you can visualise yourself dealing with scary situations successfully you have a better chance of doing so in real life. Don't shut people out, remember that if the roles were reversed you would want to help and support them.

Younger stroke groups

Organisations such as CHSS and Different Strokes help younger people who have had a stroke to get together and share their personal experiences. Many people have benefited from

having somewhere to go and the opportunity to give and receive encouragement.

Having a sense of shared responsibility to do well and help each other gives people a really positive outlook.

Success with new activities can be celebrated and there is a freedom from ‘old self’ comparisons. All of these things help to rebuild confidence and get back out in the world.



CHSS has designated young

stroke support in some areas; contact Head Office to ask for details.

Travel and holidays

Contact your local council offices for information about travel concessions and disabled parking.

CHSS factsheet ‘Holiday Information’ has ideas about how to arrange the help you might need when travelling and organisations that can help you organise a trip. Other CHSS factsheets ‘Air Travel’ and ‘Sympathetic Insurance Companies’ are also helpful.

Whether to fly

Deciding to fly after having a stroke is a very individual decision to make. You need to discuss with your doctor the variety of issues that may affect you and balance the possible and uncertain risks of flying against the benefits. Therefore you need to consider the risks, practical issues, insurance and airline regulations.

Sport and leisure

Apart from the pleasure and skill involved with sport it is vital that you keep as active as possible after your stroke. Physiotherapy is not the only form of exercise. It is important to continue the work done with therapists and build other activities into your routine. Many people find it difficult to see the end of therapy as a positive thing, but it can be – it means getting on with the rest of your life. Ask your therapist for advice on how you can maintain the level you have reached and /or progress on your own. Try and explore other options, preferably with written information about them that might be available to you.



Sporting activities you enjoyed prior to your stroke might seem out of the question but you'd be surprised what you can do if you're determined enough e.g. one handed golfing, skiing clubs or wheelchair sports, and it is possible

to adapt equipment for individual use. Speak to your physiotherapist or your own doctor about what level you should work at and set goals to progress safely and within your capabilities.

Your local council will be able to provide information about swimming clubs, exercise classes, accessible venues or contact one of the sporting organisations which help people with disabilities.

Driving after a stroke

A stroke may affect your ability to move, see, remember or concentrate. This may make it difficult or unsafe to drive, at least temporarily. For safety reasons, the DVLA (Driver and Vehicle Licensing Agency) has strict guidelines about who may and may not drive. The procedure for Group 1 (cars and motorcycles) is as follows:

- You are **not** allowed to drive for at least one month after a stroke or a TIA
- After a month **if you are considered fit to drive by your doctor and you have a full driving licence** you may resume driving. In this case you **do not** have to notify the DVLA
- After a month, if you are **not** considered fit to drive by your doctor, then the DVLA must be notified and you cannot drive.
- The DVLA will send you back a questionnaire to fill in requesting: a) your permission to contact your doctor for further information about your condition if necessary and b) offering you different options about how to proceed.



One of the options given will be to temporarily surrender your licence. This means that you do not intend to drive until your GP considers you safe to do so at a later date. No further action will be taken by the DVLA at this time. **This does not mean that your licence is revoked.** If at a later date you wish to resume driving you must apply to the DVLA for your licence back. They will then seek information about your fitness to drive.

If at the time of notification you do not choose to surrender your licence the DVLA will immediately begin its enquiries about your fitness to drive. If you are not yet fit to drive the DVLA may revoke your licence.

If you or your physician would like further clarification, or are unsure whether notification is required:

Information is available on the government website www.direct.gov.uk or you can phone the Medical Helpline on 0870 600 0301 or write to Medical Advisors, DVLA, Longview Road, Swansea SA99 1DA or Email: medadviser@dvla.gsi.gov.uk

To notify DVLA of your medical condition:

Phone 0870 600 0301 Monday to Friday, 8.00 am to 5.30 pm and Saturday, 8.00 am to 1.00 pm alternatively, you may fax the information to Fax: 0845 850 0095 or Email: EFTD@dvla.gsi.gov.uk

See the CHSS factsheet 'F9 Driving after a stroke' for more detailed information about driving after a stroke and about driving Group II vehicles.

FAMILY LIFE

Coping with parenthood

Young children and babies can be very demanding. Caring for them can be extra difficult when tiredness and thinking problems are present.

You may find that you need to ask for help to care for your children after your stroke. Accepting help is a practical solution to a practical problem, not a failure, or a sign that you can't cope. You can get help and support from organisations concerned with parenting and disability. See Useful Contacts section for details.



Disability, pregnancy and parenting *international* (DPPi)

DPPi is an organisation for disabled people who are already parents and those who wish to become parents, professionals and organisations concerned with disability and/or pregnancy and parenting. They provide advice, information, support and resources. DPPi also works closely with the Disabled Parents Network (DPN).

The Disabled Parents Network aims to:

- Provide peer support, information and advice to disabled parents.
- Remove the physical and social barriers limiting or denying disabled parents' ability to take part in society on an equal basis with non-disabled parents.

- Provide or assist in the training of disabled parents, volunteers and others working with them, and work for the advancement of education of the general public.

Pregnancy

Following stroke there is no reason why you cannot conceive, have a normal pregnancy and have a healthy baby. Thorough investigations will be done to try and establish why your stroke happened and in many cases the underlying cause can be treated successfully. This can reduce any risk to your health if you become pregnant to the same level as that of any one else. However, it is advisable for each individual to discuss planning a pregnancy thoroughly with your doctor or health visitor.

Contraception

Because there is a small risk attached to taking the combined oral contraceptive pill, alternative methods of family planning may need to be explored; you should discuss these issues with your doctor.

HRT

Hormone replacement therapy (HRT) should be discussed with your doctor on an individual basis.

Sex after stroke

Your recovery from a stroke will have taken you through various stages. Somewhere down the line your mind may turn to more personal matters such as establishing or renewing a sexual relationship. If being sexually active was important to you before your stroke it is likely that you will feel that way again. However there

may be some physical and emotional issues that now have to be considered. There are often simple measures such as experimenting with changes of position that can help overcome restrictions such as tiredness.

- Fear

The common fear following a stroke is that having sex will bring on another stroke. There is no reason why after a couple of weeks you cannot begin to have sex if you feel ready to do so. Medical evidence supports this. If you still feel unsure about having sex then arrange to speak to your own doctor.

- Emotional changes

Both men and women experience similar emotional problems after a stroke. How you feel about yourself and how you perceive others feel towards you, can lead to you losing confidence in yourself. It can take time to adjust to and come to terms with the changes in your life after a stroke and many people experience anxiety and depression as a result. This can have a knock on affect on your desire for sex. You can express your feelings in many different ways, through talking but also with body language and physical contact such as kissing and cuddling. Taking the first step may be the biggest hurdle to overcoming your anxiety and shyness about resuming sexual contact.



- Change in relationships

Retaining closeness and intimacy within your relationship will help to overcome difficulties. It is important to keep communicating with each other. There can be a subtle change within a relationship when a partner becomes a carer, especially when assistance is needed with personal care. This can sometimes cause embarrassment or affect the way you feel about each other.

See the CHSS booklet 'Sex after stroke illness' for more information.



Carers

There is no denying the impact a stroke has on the family and or partner of someone who has had a stroke. There may be many practical changes to deal with as well as adopting and adapting to a caring role. Increased costs, difficulty accessing services and coping with the distress these things can cause, can be hard. Living with any anger,

guilt and frustration of the person affected can have a profound effect on individual family members and the family as a whole.

It is very important for carers to look after themselves and to have the possibility of 'time out'. Help and support is available through Social Services, your Health Visitor, Carers' Centres, GPs and organisations such as CHSS in the form of young stroke and carers' groups.

See the CHSS booklet 'Stroke: a carer's guide' for more information.

FINANCE AND WORK

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 other costs such as travel to and from hospital.

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

Your local Department for Work and Pensions (formerly known as the Benefits Agency) will deal with your benefits.

Independent Advice

- Citizens Advice Bureau

Local advice centres such as Citizens Advice Bureau (CAB) know their way round the benefit system and can give you independent advice if you are trying to work out what you should claim for.

- Information from your local council office

Your local council office will be able to give you details about local welfare or benefits advice centres that you can visit or phone. These are often attached to the social work department's offices. They can also provide you with information about local transport concessions, such as disabled parking and travel services.

- Princess Royal Trust Carers' Centres

Many Carers' centres have access to welfare rights advice as well as lots of useful local information about services, activities and sources of help.

Personal support grants programme

CHSS provides small grants to people in financial difficulty for items ranging from clothing and bedding to holidays or respite care. Applications are submitted through your local social work department or by health professionals. Contact the Personal Support Grants Administrator at CHSS Head Office for further details.

Returning to work

People with less severe strokes are often able to return to work within a few months. The effect of a more serious stroke on a young person however can be very traumatic and devastating. As well as the losses the stroke has caused physically and psychologically, there is also a huge impact on a working person's life in terms of earning a living and their role within their family and society.

Try not to compare what you can do now to what you used to do. Tiredness, cognitive problems like memory loss and difficulty concentrating can cause as many hurdles in the work place as physical disability.

Taking up fresh opportunities

Many people find it an opportunity to try something else, retrain, work from home, work flexibly and take up new challenges and opportunities.

- Working in the voluntary sector can be a great way of building up confidence, helping to get back in to a working environment and being with other people.
- Voluntary work can also be very fulfilling and important. It can be a great way of keeping occupied until you are ready to decide where your future lies. Contact your local Volunteer Centre.



- See a Disability Employment Advisor at your local job centre. They will be able to give you advice about careers and retraining.

This could be an opportunity for a complete change maybe taking you into an area you always were interested in.

- You may be referred to organisations that specifically provide opportunities for people with disabilities such as Momentum or Workability.
- Contact the CHSS Advice Line for their Computer Factsheet. It has details about computer courses specifically for disabled people and organisations such as Abilitynet.
- Resume education, contact Learn Direct or LEAD (Linking Education and Disability) Contact local colleges and universities for further information.

If you do return to your previous employment

- It is very important that you speak frankly to your employer and close colleagues so that you do not put yourself under too much pressure to perform.
- Some people can be unrealistic about returning to work and take on too much too soon. Give yourself a chance and don't be too hard on yourself if things don't work out the way you want them to.
- Remember to take travel arrangements and travel time into consideration well in advance.

- Working reduced hours and with a reduced workload, to begin with at least, is sensible as you may become over-tired which makes things more difficult. Flexible working patterns are best suited especially if you have good and bad days. Working every day might be too much to begin with.
- Try to remember that many people **do** make a success of returning to work. Many people with less severe strokes returning within three months of having their stroke.



GETTING HELP FROM CHEST, HEART & STROKE SCOTLAND

Community services provides a variety of support to meet the individual 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 stroke illness.

Personal Support and Research Grants

CHSS also provide personal support grants throughout Scotland and funds research into stroke.

Information

A full range of booklets and fact sheets are available by contacting the Publications Department.

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 stroke nurses in Dumfries & Galloway, Fife, Forth Valley, 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.

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

FURTHER READING

Useful further reading on life experiences of stroke

Diary of a Stroke

By Martin Stephen (2008) Psychology News Press ISBN 978-0-90763-310-5

Martin Stephen was at the pinnacle of his career when he suffered a stroke. In this diary, the head of St Paul's - one of Britain's top private boys' schools - and author of the hugely popular Henry Gresham crime thrillers describes how it felt to have his body thrown terrifyingly out of control, and how he refused to let it beat him.

£12.99

Stroke survivor-a personal guide to recovery

By Andy McCann (2006) Jessica Kingsley ISBN 978-1-84310-410-0

At the age of 37 Andy McCann was physically fit, strong and in good health. Then, mid-way through instructing his weekly martial arts class, he experienced a stroke and was rushed to hospital. Until then, the word 'stroke' had meant little to Andy, and in this book he recounts the many difficulties in learning to live with his new situation.

£12.99

Surviving a stroke

By Mike Ripley (2006) White Ladder Press ISBN 978-0-95482-198-2

In January 2003, at the age of 50, Mike Ripley had a stroke. This is his story of the stroke

itself and the next year in the recovery process, together with a mass of practical tips and advice for anyone else recovering from stroke. As a comic crime thriller writer, Mike Ripley looks for the humour in any situation, and finds it even in this one.

£7.99

My Stroke of Luck

By Kirk Douglas (2002) ISBN 0316859982

Published by Little Brown and Co Ltd,

Brettenham House, Lancaster Place, London

WC2E 7RN

The actor's personal and inspiring account of his experience of having a stroke.

£12.99

My Year Off – Rediscovering life after a stroke

By Robert McCrum (1999) Picador

ISBN 0330352407

The author was the literary editor of the Observer when at the age of 42 suffered a stroke. He has written this book about the story of his year of recovery. It is in the process of being made into a film.

£7.00

The Diving Bell and the Butterfly – A memoir of life in death

By Jean Dominique Bauble (2002) Forth Estate

ISBN 0007139845

The authors own experience of stroke dictated with only the use of his left eyelid. A remarkable book about his experiences locked inside his body (locked – in syndrome).

£6.99

A Stroke of Genius

By Mick Sutton (2003) Diadem Books

ISBN 0-595-27855-8

A collection of letters and postcards written by the author to his Speech and Language therapist, while on a world cruise. This book is a saga of recovery and an inspiration for others who have to

USEFUL SOURCES OF AIDS, GADGETS AND HOME SHOPPING

Disabled Living Foundation

380-384 Harrow Road

London

W9 2HU

Helpline: 0845 130 9177

Textphone: 0207 432 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.

Mail order catalogues:

Make your choices from home without trailing round the shops. You may also be able to shop on line e.g. Betterware, Innovations, and Argos. Phone the CHSS Adviceline for a copy of the factsheet 'Mail order catalogues for aids and equipment.'

Shop on-line

Do your grocery shopping online and delivered to your door for a delivery charge of about £5. This service is available from many major supermarkets.

USEFUL ADDRESSES AND WEBSITES

Ability Net Scotland

PO Box 28423

South Queensberry

EH30 9ZN

Telephone: (0131) 331 6381

Fax: (0131) 331 7418

E-mail: scotland@abilitynet.co.uk

Website: www.abilitynet.org.uk

Ability Net is a Charity offering an information service to people with disabilities, and others seeking advice on computer technology.

Activities include consultancy and assessment services to assist in choice and use of computer equipment at work and at home.

Adapt-IT

Trafalgar House

Greenville Place

Mill Hill

London

NW7 3SA

Tel: 0845 644 1712

Fax: 020 89590 844

Website www.adapt-it.org.uk/

Email: info@adapt-IT.org.uk

Adapt-IT has been established to help disabled people to make full use of computers. A range of IT products are for sale on line. A catalogue is available on request.

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.

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.

Depression Alliance Scotland

11 Alva St,
Edinburgh
EH2 4PH.

Tel: 0845 123 23 20

(10am - 2pm Mon, Tues, Thurs and Fri)

Email: info@dascot.org

Website: www.dascot.org

Depression Alliance Scotland is working towards a future where depression is recognised, understood and acknowledged to be a common and treatable medical condition, just like any other. They run a telephone information service and self-help groups as well as producing a number of publications about depression.

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. Their website is very interesting and informative. Different Strokes provides information, support, a telephone service and counselling. Exercise opportunities also available but very limited in Scotland.

Disability UK

Website: www.disabilityuk.com

This website provides numerous links and pages of information on all topics to do with disability, from transport to safety.

Disability, Pregnancy & Parenthood international

National Centre for Disabled Parents

Unit F9, 89-93 Fonthill Road

London N4 3JH

Freephone: 0800 018 4730

Fax: 020 7263 6399

Textphone: 0800 018 9949

E-mail: info@dppi.org.uk

Website: www.dppi.org.uk

Disabled Parents Network

Helpline: 08702 410 450

Email: e-help@disabledparentsnetwork.org.uk

Website: www.disabledparentsnetwork.org.uk

LEAD

Tel: 0131 317 3439

Email: enquiries@lead.org.uk

Website: www.lead.org.uk

Linking Education and Disability, enables disabled adults to access education and learning opportunities. Contact head office number above for your local area services.

learndirect scotland

learndirect
 FREEPOST SCO5775
 PO Box 25249
 Glasgow G3 8XN
 Helpline: 0808 100 9000
 Email: info@learndirectscotland.com
 Website: www.learndirectscotland.com

learndirect is a free and confidential telephone helpline and website for adults looking for impartial information and advice on courses and careers. Open Monday to Friday from 7:30am to 11pm. Saturday and Sunday between 9am and 6pm.

Scotland's Healthy Living Campaign

Healthy eating and exercise advice from the Scottish Executive.
 Helpline: 0845 278 8878
 Website: www.healthyliving.gov.uk

Scottish Disability Sport

Caledonia House
 South Gyle
 Edinburgh EH12 9DQ
 Tel: 0131 317 1130
 Fax: 0131 317 1075
 E-mail: ssadsds2@aol.com
 Website: www.scottishdisabilitysport.com

Formerly the Scottish Sports Association for Disabled People the organisation was formed to provide facilities for and to encourage the development of sport and physical recreation for disabled people.

Sexual Dysfunction Association (SDA)

Suite 301, Emblem House,
 London Bridge Hospital
 27 Tooley Street
 London SE1 2PR
 Helpline: 0870 7743571
 E-mail: info@sda.uk.net
 Website: www.sda.uk.net

The SDA is committed to helping and supporting people, and partners of people, with all forms of sexual dysfunction by raising awareness and providing information and education on male and female sexual problems.

Speakability

1 Royal Street
 London SE1 7LL
 Tel: 020 7261 9572
 Fax: 020 7928 9542
 Helpline: 0808 808 957
 Email: speakability@speakability.org.uk
 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.

Volunteer Centres

www.volunteerscotland.org.uk

**Phone/Textphone the Chest,
Heart & Stroke Advice Line for
confidential, independent advice
from one of our nurses.**



**The line is open
Monday – Friday
9.30 – 12.30 and 1.30 – 4.00**

0845 077 6000

Charged at local call rate.

Out of hours answering machine.

Email: advice@chss.org.uk

Fax: 0131 220 6313

The information contained in this booklet is based on current guidelines and is correct at time of printing. The content is also put out to peer, patient and expert review. If you have any comments about this booklet please contact Lorna McTernan, Health Information Manager, at the address on the facing page.

STROKE PUBLICATIONS

Stroke: a guide to your recovery	Driving after a stroke
Stroke: a carers guide	10 common questions asked after a stroke
Reducing the risk of stroke	Mouthcare after a stroke
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Stroke in younger people	Positioning and stroke
Coming to terms with a stroke	ACT FAST
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Living with high blood pressure	
Aphasia Stroke Journey:	Holidays
Part 1 Early days	Insurance companies
Part 2 Rehabilitation	Suggested booklist
Part 3 Moving On	Air travel for people affected by chest, heart and stroke illness
Conversation Support Book (one copy free) £5	Diabetes: links with heart disease and stroke
	Coping with tiredness
	MCNs & You
	Illustrated risk factors (ethnic target)
	Illustrated risk factors (general target)
	How to make the most of a visit to your doctor
	Living with stress and anxiety
	Healthy eating
	Understanding help in the community
	Glossary
	Just move!
Stroke Matters £5	
Salt	
Cholesterol	
Warfarin	
Helping communication after stroke	

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

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103 Clarkston Road

Glasgow G44 3BL

Open Mon – Fri

Inverness

Tel: 01463 713 433

Fax: 01463 713 699

5 Mealmarket Close

Inverness IV1 1HT

Open Mon – Fri

Coffee shop open

Mon – Sat



Chest, Heart & 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 £5 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.

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

Monday – Friday

9.30am - 12.30 and 1.30pm - 4.00pm

0845 077 6000

Fax us: 0131 220 6313

Email us: advice@chss.org.uk

Text us: text chss followed by your message to 07766 40 41 42

Chest, Heart & Stroke Scotland and CHSS are operating names of The Chest, Heart & Stroke Association Scotland, a registered Charity No. SCO18761

February 2009