

STROKE SERIES SS8

COMING TO TERMS WITH A STROKE





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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INTRODUCTION

Immediately after a stroke the main focus is usually on the initial recovery period, finding any possible causes for the stroke, and reducing any risk factors you may have such as high blood pressure etc. These areas are dealt with in detail in the CHSS booklet ‘Stroke: a guide to your recovery.’

Having a stroke is a major life event which often happens out of the blue and brings unexpected changes to your life. After an initial recovery period life will start to settle down and coming to terms with having a stroke may become more important. This booklet aims to look at the ‘emotional’ recovery from stroke.

Unique experience

It is important to recognise that everyone will have their own unique individual experience of stroke.

Nobody else really knows what it is like for you to have had a stroke apart from you. Although other people will try to understand and want to help it can be very difficult for the person who has had the stroke to explain how it feels. However, knowing that some of the difficulties you may experience after a stroke are recognised and understood by others, will hopefully encourage you to seek help if and when you need it.

The author would like to take this opportunity to thank the various health professionals and people who have had a stroke who contributed to the writing of this booklet.

Loss of speech and use of language

When speech and language is affected after a stroke it is called aphasia or dysphasia. It is incredibly frustrating and affects people to a greater or lesser degree depending on the location and severity of their stroke. The inability to express oneself must be addressed and some form of communication established. This is why it is so important to seek the help of a speech and language therapist and utilise anything that may be of help such as stroke groups, supported conversation, computers and communication devices, as appropriate.

For more information contact the CHSS Advice Line 0845 077 6000 or Speakability – an organisation specialising in aphasia see contact details in useful addresses and websites section.



WHY ME?

‘Why me?’ is the most commonly asked question of all. Hopefully you will have found the cause of your stroke – but not everybody does. Asking is often the first step in coming to terms with having a stroke and the beginning of making adjustments after a stroke. Accepting that your life can not be exactly the way it was before and overcoming the feelings of loss and fear you may experience is a big part of your emotional recovery.

A grieving process

Stroke often happens suddenly, without warning, and can cause overwhelming feelings

of shock and loss. In fact it is not uncommon for people who have had a stroke to say they feel like part of them has died. Many people affected by stroke, and their families, can experience similar emotions as in a grief reaction such as: shock, denial, anger, guilt as well as fear and depression.

It is important to recognise that these feelings are normal responses to a major life event and can occur at different times. In

time most people move forward in adjusting to life after a stroke and to accepting the changes in themselves.



Here are some of the commonest grief related emotions which can be experienced after a stroke:

Shock	Shocked into inaction, feeling that what is happening is not real.
Denial	Initially denial protects you from being overwhelmed by the changes in your life. Some people may become 'stuck' in denial and are unable to make progress in coming to realistic terms with the effects of their stroke. (*Note: see section below on denial)
Anger	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 a loved one, with the doctors and nurses for not doing enough for you or for not preventing the stroke. Anger is often directed at those closest to you, which can easily be misunderstood.
Guilt	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.

Denial*

Denial can also frequently be a lack of insight into what has happened due to damage to thinking processes (or cognitive effects) because of a stroke. In this case it can seem as if the person is actively denying the problem and the family might blame them for this, when in fact the person can not do anything about it.

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

Loss

There are many examples of how a sense of loss may be felt during your recovery process. These losses may not be that obvious to other people but they are part of what makes up your personality and sense of self worth. Such as:

- loss of physical ability
- loss of decision making
- loss of identity
- loss of confidence
- loss of dignity
- loss of control
- loss of sense of purpose
- loss of income
- loss of independence and roles in family, work and social life

**Fear**

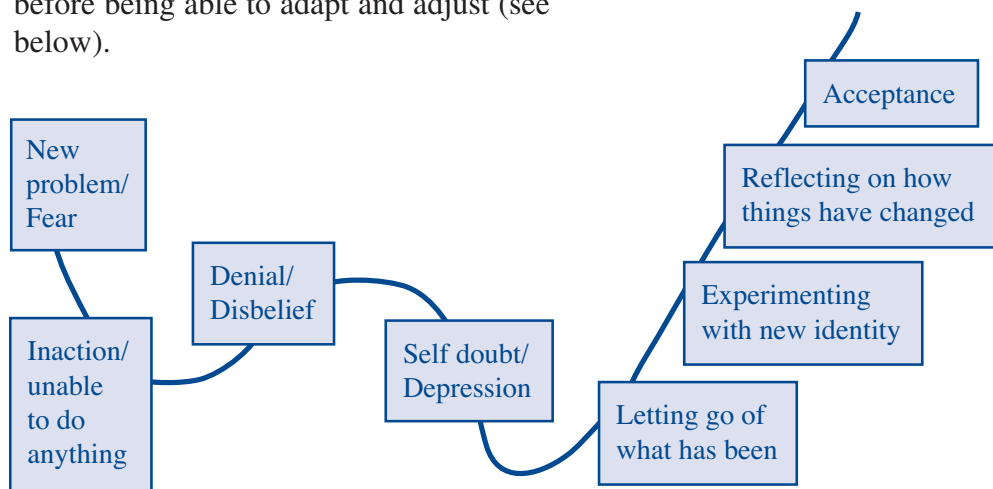
Anxiety after a stroke is often related to feelings of fear. Fear of dying, fear of having another stroke, fear of the unknown, fear of loss, fear of failing. Life after a stroke is made up of ups and downs and fear can catch you out when you are not expecting it.

How to cope with anxiety is covered in more detail later on.

ACCEPTING CHANGE

Pattern of accepting change

Any big change in life brings about emotional reactions. Psychologists have identified stages of how people feel going through change or transition. These stages can be plotted on a graph to show that it is normal to feel worse before being able to adapt and adjust (see below).



Small achievable goals

Recovery from stroke is usually a gradual one made up of small but significant achievements.

The pattern of accepting change above can also be applied to the smaller goal setting challenges that make up recovery.

Even though a new goal may seem frightening you can achieve it or adapt it to one you can achieve.

In this way you can keep positive about your achievements and reassure yourself that you can overcome problems, because you have in the past.

Some people find their ‘unrealistic goals’ can be a major source of motivation even if further on they realise they were not achievable. Above all it is vital to remain as optimistic as possible. This is why recognising depression is so important.

Remember that having good days and bad days is natural and there are limits to what you can achieve in any one day.

How you feel about yourself

Having a stroke can affect how you feel about yourself in many ways:

- having an altered body image (feeling that you look different)
- having an altered sense of self (feeling different about yourself)
- having a sudden dependence on other people
- the transition from being able bodied to disabled
- feeling low in mood or depressed
- having an altered sexual identity and sexual relationships (*See the CHSS booklet ‘Sex after stroke illness’ for more information*)
- waiting to get back to ‘normal’, to take up your life where you left off

Effect on other people in your life

Most relationships are complex and we have very different relationships with different people. What we don’t always realise is how much our relationships with other people can be affected by the way we feel about ourselves.

Try to remember that other people may:

- lack understanding of how you are feeling
- benefit from sharing your thoughts and feelings
- have been affected by your stroke too
- be too scared to talk about their own fears and worries

Staying focused

Fight feelings of isolation by asking family members to get involved in your rehabilitation and care. At the same time strive for as much independence as you can and use any opportunities that arise to boost your confidence e.g. getting involved in making decisions, asking for help with your appearance, becoming familiar with your abilities and obtaining more information about your condition and progress.



Blaming stroke for other things going wrong

Coming to terms and adjusting to effects of your stroke will not mean an end to other problems in your life. This can be a harsh reality for some people. Pre-existing difficulties will still be there e.g. relationships, marital problems, financial, work and other unresolved issues. Remember life is unpredictable and uncertain – with or without a stroke.

Letting go – adjustment and acceptance

Letting go happens when you can see yourself as you are now and not as you used to be – accepting the loss of your ‘old self’. To get there you will reach a period where you are able to start looking at your ‘new’ identity. You may start to reflect on what has happened, how things have changed and to look at your recovery. Then you might find yourself imagining situations and visualising yourself in places as you are now and not as you used to be. This discovery of your new self image will include your new way of looking / feeling / ability to function. So this process leads to acceptance of your new identity and living with stroke.



TALKING THERAPY

Being able to talk about how you feel is healthy but not always easy! Some people find they just can not talk to family members about how they really feel about a situation. Some find they can open up to a stranger or someone involved in looking after them, such as a doctor or stroke nurse, more easily. Some people benefit from talking to someone with special training. This kind of help is called 'Talking Therapy' and it includes Counselling and Cognitive Behavioural Therapy. If you go for any talking therapy remember to let the therapist know if you have poor concentration or fatigue. If you have memory problems, ask for a written copy summarising the sessions and any actions to be taken.



Counselling

Counselling generally allows people to explore various aspects of their life and feelings which are causing distress. Bottled up feelings such as anger, anxiety, grief and embarrassment can become very intense and counselling offers an opportunity to explore them, with the possibility of making them easier to understand.

Counselling does not include giving direct advice.

Cognitive Behavioural Therapy (CBT)

This focuses on how you think about yourself, the world and others as well as how your thoughts and actions affect your feelings. Working with a therapist can help you to change how you think (cognitive) and what you do (behaviour). These changes can help you to feel better. CBT focuses on ‘here and now’ problems and difficulties. Instead of focussing on the causes of your distress or symptoms in the past, it looks for ways to improve your state of mind now.



COPING WITH DEPRESSION

Feeling down for some of the time is 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?

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. Some symptoms may be present as a result of your stroke such as tiredness, 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, as described earlier, but these should not cloud the possibility that you may be depressed and benefit from treatment.

Symptoms of depression

Most experts agree that if you have experienced four or more of these symptoms for most of the day, nearly every day, for over two weeks then you should seek help. Though you may, at first, find it difficult to bring the subject up speak to your doctor if you think you might be depressed.

- 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

Taking antidepressants

Your doctor may suggest that you try taking antidepressants. There are several different types used depending on your symptoms and medical history. A chemical imbalance in the brain is a possible factor for depression in some people. This can be successfully altered with an antidepressant. Antidepressants are not the same as tranquillisers and they are not addictive. However, use has to be monitored and they shouldn't be stopped suddenly. If your doctor suggests antidepressants make sure you agree to a further appointment to review your progress.

Taking antidepressants does not have to be a long term solution. Many people are helped through a difficult time in their lives because antidepressants allow

them a temporary platform to stand on until they can come to terms with a new life. Then they are able to cope better and move on when they have adjusted to issues affecting them.

Who else can help?

Sometimes further support may be needed. Many people get support and advice from their doctor, stroke nurse or a therapist who is working with them.



Some kind of talking therapy as well as antidepressants may be helpful.

Most people won't need to see a psychiatrist unless their depression is very severe or they are suicidal. You may be referred on to the community mental health team for support.

Other ways to help yourself

- Most people find they have good and bad days and this is true of having a stroke and of depression.
- Get outside if you can - fresh air can help.
- Eat as healthy and varied a diet as you can.
- Try to avoid alcohol, it will bring your mood down and can make sleeping patterns worse.
- Try not to worry if you don't sleep. Read, listen to the radio or TV. Your body is still resting by lying down.
- When you are low it can be difficult to make decisions – talk to those people you trust.



COPING WITH ANXIETY

Some people experience anxiety after their stroke, for some this can be quite severe and disabling. Anxiety can affect you in many different ways: physically, emotionally and the effect it has on your behaviour. Seek some help and advice. Listen to nurses / carers / family who can see your mood / behaviour changing.

Possible physical symptoms of anxiety

People often mistake anxiety symptoms for illness. Once you recognise that your symptoms are anxiety related you can learn to control how you feel, putting you back in charge. This is not always easy as it can be difficult to be sure what is anxiety related and what is not. Anxiety related symptoms include:

- headaches
- muscle tension or pain
- stomach problems
- sweating
- feeling dizzy
- bowel or bladder problems
- breathlessness or palpitations
- dry mouth
- tingling in body
- sexual problems

Possible emotional problems linked to anxiety:

- feeling irritable
- feeling tense

- feeling low
- feeling of apathy
- feeling low in self esteem

Possible effects on behaviour:

- withdrawing from usual activities
- avoiding seeing other people
- trying to rush around and hurry things
- constant worrying
- becoming unreasonable
- being forgetful or clumsy
- temper outbursts
- drinking or smoking more than normal
- changes in eating habits

Learn to control your anxiety

Concentrate on how you actually feel and not how you imagine you are going to feel. If you experience physical symptoms as part of anxiety tell yourself that you are not ill and that the symptoms will pass if you take control of them.

Replace negative thoughts with positive thoughts by reminding yourself that you have tried something before and nothing bad happened and so you can do it successfully again.

Visualise yourself going into a difficult situation and coming out with a successful outcome.

If you have to do something that you are not looking forward to ask yourself if there is anything you can change to make it easier.

Try to remember that most things are never as bad as you imagine they are going to be.

Prepare yourself

Practise relaxation and breathing techniques to help you cope with stressful situations or any situation that makes you feel anxious. If you become confident about how to use these techniques, it will be much easier for you to use them when you actually need them.

Learn a relaxation technique

There are many different methods of relaxation you can try. The main thing is to practise until you are able to focus on how it feels to be relaxed more and more quickly. This skill can then be used at times of stress as well as giving you the added benefits of regular relaxation.

Most methods require a comfortable sitting or lying position in a quiet peaceful environment with soft lighting. Try to avoid distractions and interruptions.

By focusing on your breathing and relaxing of muscles you will find that you relax.

Relaxation tapes are available from bigger bookshops and look out for local relaxation classes. Many people who have had a stroke find a relaxation tape very beneficial.



Learn breathing control

This is a very simple way of learning how to breathe in a relaxed manner and also to restore normal breathing when you are anxious.

It involves gentle breathing using the lower part of your chest, with the upper chest and shoulders relaxed. It is very important to breathe normally and not to hold your breath or take deep gasps.

- Settle yourself in a relaxed position.
- Make sure that your back is supported.
- Rest your hands on your lower rib cage / stomach.
- Keep your shoulders and upper chest relaxed.
- Feel the gentle rising and falling under your hands as you breathe in and out.
- Find a rhythm that is comfortable for you. A general guide is to count in for four and out for four.
- Concentrate on the lower part of your chest moving rather than the upper part.
- Do not try to take deep breaths.

The more you practise this the easier it becomes. You will then be able to practice it standing as well as sitting.

Try practising regularly throughout the day and over time you will be able to use it whenever you are anxious. Some people find it easier to learn a relaxation or breathing technique with the help of a professional.

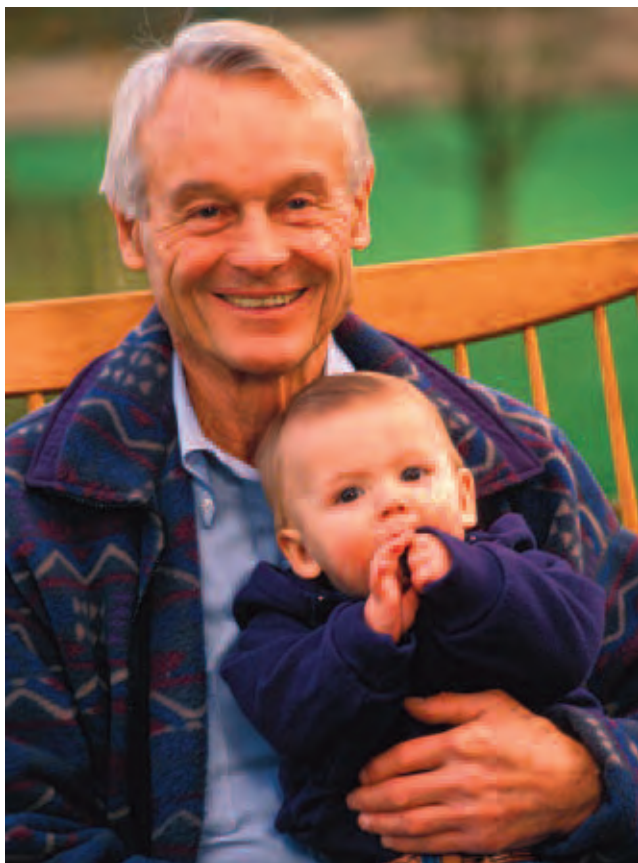
Other ways to help yourself

- seek help through talking therapy
- contact an organisation such as Anxiety UK or No Panic
- ask the CHSS Advice Line for additional written material about panic attacks



THE FUTURE

Having a positive attitude to your recovery will help in many different ways. By taking steps to help yourself as much as possible you can begin to overcome some of the feelings that have been discussed in this booklet. Seeking help and advice from others will help you and your family to find solutions to difficult problems. Sharing your experience with others and communicating how you feel as best you can will help you to come to terms with having a stroke and to look forward to the future.



Chest, Heart & Stroke Scotland

65 North Castle Street

Edinburgh

EH2 3LT

Tel: 0131 225 6963

Fax: 0131 220 6313

Advice Line: 0845 077 6000

Website: www.chss.org.uk

CHSS aims to improve the quality of life for people in Scotland affected by chest, heart and stroke illness through medical research, advice and information, and support in the community.

The Adviceline nurses can provide confidential, independent advice on all aspects of chest, heart and stroke illness to those affected, their families and health professionals.

Different Strokes

9 Canon Harnett Court

Wolverton Mill

Milton Keynes

MK12 5NF

Helpline: 0845 130 7172

Fax: 01908 313 501

Email: info@differentstrokes.co.uk

Website: www.differentstrokes.co.uk

UK charity set up by younger stroke survivors for younger stroke survivors providing information and support.

**USEFUL
ADDRESSES AND
WEBSITES**

Speakability

1 Royal Street

London

SE1 7LL

Tel: 020 7261 9572

Fax: 020 7928 9542

Email: speakability@speakability.org.uk

Information Service and Helpline: 080 8808 9572

Website: www.speakability.org.uk

Speakability is the national charity dedicated to supporting and empowering people with aphasia and their carers. Speakability offers impartial information and support through its helpline, website and training courses, and distributes its own fact sheets, low-cost publications and videos.

Anxiety and depression contacts:**Anxiety UK**

Zion Community Resource Centre

339 Stretford Road

Hulme

Manchester

M15 4ZY

Helpline: 08444 775 774

(Mon - Fri 9.30 am - 5.30 pm)

General information: info@anxietyuk.org.uk

Email support service: support@anxietyuk.org.uk

Website: www.anxietyuk.org.uk

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.

No Panic

93 Brands Farm Way

Telford

England

TF3 2JQ

Tel: 01952 590 005

Helpline: 0808 808 0545

Email: ceo@nopanic.co.uk

Website: www.nopanic.org.uk

No Panic offers support to people with anxiety.

Breathing Space

Phone line: 0800 83 85 87

Email: info@breathingspacescotland.co.uk

Website: www.breathingspacescotland.co.uk

The phonenumber is open 24 hours at weekends (6pm Friday - 6am Monday) and from 6pm to 2am on weekdays (Monday - Thursday).

Breathing Space is a free and confidential phonenumber service for any individual, who is experiencing low mood or depression, or who is unusually worried and in need of someone to talk to.

Finding a therapist through professional bodies:

British Association for Counselling and Psychotherapy (BACP)

Website: www.bacp.co.uk

BACP has a 'find a therapist' section on their website with local contacts and their specialties.

Royal College of Psychiatrists

Website: www.rcpsych.ac.uk

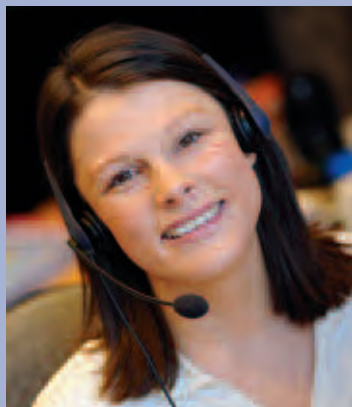
The section on their website called Mental Health Information includes written information about depression and many other topics to do with mental health. To see a psychiatrist, as with any medical specialist working in the NHS, you will need to get a referral from your GP. The College is unable to supply names of members, or recommend individuals. Try your GP, Private clinics or local yellow pages for psychiatrists who practice privately.

The British Psychological Society

Website: www.bps.org.uk

To see a psychologist, as with any medical specialist working in the NHS, you will need to get a referral from your GP. However, The Directory of Chartered Psychologists available on the website details Clinical Psychologists, some of whom may offer private sessions.

**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: adviceline@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

	F9	Driving after a stroke
SS1		Stroke: a guide to your recovery
SS2	F10	10 common questions asked after a stroke
SS3	F11	Mouthcare after a stroke
SS4	F12	Contenance problems after stroke
SS5	F14	Eye problems after stroke
SS6	F15	Memory problems after stroke
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SS8	F25	ACT FAST
SS9	F27	HRT and stroke
SS10	F29	Swallowing problems after stroke
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	F26	Understanding help in the community
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		Stroke Matters £5
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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.

Designed by Creative Link, North Berwick

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

