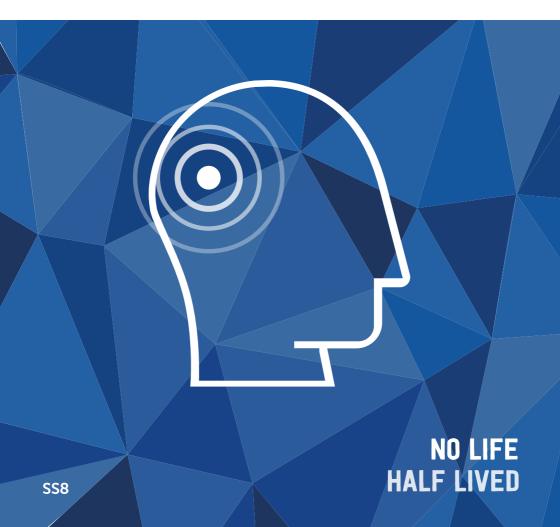


COMING TO TERMS WITH A STROKE





NO LIFE HALF LIVED

The information contained in this booklet is based on guidelines and practice and is correct at time of printing. The content has undergone peer, patient and expert review.

COMING TO TERMS WITH A STROKE

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ABOUT THIS BOOKLET

COMING TO TERMS WITH A STROKE

Who is this booklet for?

This booklet is for people who have had a stroke. You may also find it useful if you are a friend, relative or carer of someone who has had a stroke.

What is this booklet about?

The booklet can help you understand how your stroke might affect your feelings and emotions. It suggests ways to help you cope with some of the difficult feelings you might be having. It also provides information on further help and support available to you.

How to use the booklet.

The booklet is divided into different sections. These are outlined in the contents list. You do not have to read all of the sections at once. Some sections may be useful to you now, other sections you may want to come back to and read at a later time.

Further information

If you would like more information, we have a range of booklets and easy-to-read 'essential guides' on a number of different topics discussed in this booklet. To see the full list our resources and to order, view or download them, go to www.chss.org.uk/publications or call the Advice Line nurses for more information on 0808 801 0899.

Online resources are also available. The website www.selfhelp4stroke.org is for people who have had a stroke. It includes sections on keeping well, being active, emotional support and coping with setbacks. The website www.stroke4carers.org is for carers of people who have had a stroke. It provides practical advice and tips for carers, including support, advice for caring at home and information on money and benefits.

FEELINGS AND EMOTIONS AFTER STROKE

After a stroke people can feel a range of emotions, both positive and negative.

Below are some feelings that people often experience after they have had a stroke.

Which of these apply to you?

Why do you think you are feeling this way?

Circle how you feel right now:

frightened	helpless	lucky
content	stressed	anxious
optimistic	exhausted	proud
in denial	distressed	confident
grateful	not like yourself	eager
depressed	determined	angry
relieved	understood	guilty
motivated	hopeful	loved
frustrated	inspired	loss

It is natural that having a stroke will affect the way that you are feeling. Remember, everyone's experience of stroke is different. There is no right or wrong way to feel after a stroke, nor any set order or timetable in which you might feel these emotions. The important thing is to recognise your own emotions. Try to deal with any that may be harmful to you or your recovery and get help when you need it.

Why am I feeling like this?

Feelings such as shock, denial, anger and guilt are a normal reaction to a major event in your life, such as a stroke. Lots of people affected by stroke say that they feel something similar to a grief reaction. Others feel like they have lost the life that they had before. These are all normal feelings when you are faced with such a big change in your life.

You may also be adjusting to physical changes and you may be in pain or feel very tired because of your stroke. This can make any difficult emotions that you have seem worse.

If the part of your brain that controls emotions has been damaged by your stroke, this can affect how you feel and act. This means that you may not be able to control your mood and emotions. You may be much more emotional than usual and find that you cry in situations you wouldn't have cried in before. You may have extreme emotional reactions that are uncontrollable or not related to what is happening around you.

This is known as **post-stroke emotionalism** or **emotional** lability. You might suddenly want to cry, laugh or swear for no apparent reason. These reactions can be quite upsetting, both for you and for those around you. However, they usually come and go quite quickly and often reduce or go away over time.

About I in every 3 people will experience some emotional changes after a stroke. You will probably have to deal with lots of different feelings before you begin to understand what has happened to you and before you start to feel better. You may need to accept that life will be different from how it was before.

Many people are tempted to put on a brave face and try to ignore these feelings but this can make you feel worse and lead to problems such as anxiety and depression.

As you begin to feel stronger you will be able to focus on the future and move forward.

Common emotions after a stroke Worry, fear and anxiety

It is quite normal to have more worries or fears than usual after a stroke.

For example, you might feel:

- Worried about how you are going to cope at home, what effect your stroke is having on your family, whether you will be able to return to work, or you may be worried about money.
- Frightened about the future or that you might fail or look silly.
- **Scared** that you are going to have another stroke.

With the right help and support, these fears and worries should reduce over time. However, if you start feeling worried or anxious about lots of different things, or you don't know what is making you feel anxious, then try to talk to someone about how you are feeling. Anxiety can affect your recovery. It can affect your mood making you feel irritable, tense or low. You may also feel tearful, unable to concentrate and prone to temper outbursts, making you feel out of control.

All these feelings can make you withdraw from your usual activities.



Some people who develop anxiety after a stroke start to avoid seeing people including friends and family. You may also begin to avoid certain situations such as going out to busy shops or going on public transport. It is important to realise that this is happening and get help to face these situations and rebuild your confidence.

Relaxation exercises, listening to music, and distraction by thinking of something else can help reduce anxiety and worry. Try and adopt a more relaxed approach. Keep busy but try not to rush.

"I tried not to over-think things and to talk about my worries instead of lying awake at night and thinking about them."

Frustration

Feeling frustrated is very common after a stroke. Nearly everyone who has a stroke will feel frustrated at some point. This is quite normal.

You may feel frustrated because:

- You are not able to do the things you used to do
- You have to rely on other people now
- You can't return to work or go out as easily as before
- You are struggling to communicate
- You feel tired all the time and have little or no energy
- You keep forgetting things

It is important to try to find a way to deal with these frustrations so that they don't build up and become a big issue for you and those around you. Frustration can lead to bad moods and anger and means that you may lose your temper with your family and friends. Try to relieve your frustration by focusing on the things you can do rather than the things you can't. Exercise and relaxation can also help.

Anger

Feeling angry is a normal emotion that everybody feels sometimes. After a stroke you may feel angry more often than before or you may not be able to control your temper. This can be difficult to deal with because you are not sure why you are feeling so angry. It could be because of the damage in your brain after your stroke. Some people get angry because they are frustrated. Some anger is normal but if you are angry all the time this can affect your health and your recovery.

If you want to regain control over your anger, try to do something physical or find something to take your mind off what you are feeling angry about. Walk away from the situation that is affecting you and take time to think and calm down.

Low mood or depression

After a stroke, many people feel low or a bit down from time to time. Again, feeling low is a perfectly normal feeling as you try to come to terms with the changes in your life. But if you are feeling like everything is hopeless and you are sad most of the time then you may be depressed. Depression is one of the most common emotional changes after a stroke, affecting about 1 in 3 people. Depression can affect your mood, sleep, appetite and interest in life. It can also affect your physical recovery as it can make you feel lethargic, detached and make it harder to stay motivated as you recover.

If you are feeling sad or depressed, talk these feelings through with a healthcare professional or someone you trust.

Sense of loss

For many reasons you may feel a sense of loss after a stroke. You may feel you have lost your identity, your independence, or control over your health, or it could be that you can't physically do what you could do before. Because of this some people say that they feel they have lost the person they used to be.

These losses may not be that obvious to other people but they can affect your self-worth and personality. This can be difficult to deal with. Often people recovering after stroke say that they simply don't feel like themselves anymore. Try to remember that change can take time and while everything may not go back to how it was before, you will be able to find ways to accept, adapt and move forward.

"I realise my life might not be the same again and I am ok with that but I think my husband still hasn't come to terms with it." Karen

Guilt

Many people say they feel guilty after a stroke. It might be that you feel guilty about what may have caused your stroke or about causing stress and worry to family and friends. These feelings of guilt can be guite destructive and are often irrational.

"I feel guilty about everything, I feel I should be working again, doing more housework, stop crying so much, do the grocery shopping. My husband is fantastic and very supportive but even that makes me feel guilty that I should be better by now."

Will it get better and when?

Emotions can feel overwhelming and out of control at times. If some of these feelings do not go away completely you will get better at dealing with them over time and with help. Remember that you are not on your own. There is help and support available.

You might have to find a 'new normal' after a stroke, so listen to your body and brain, take your time and don't expect too much too soon. Recovering emotionally from a stroke can take longer than your physical recovery so don't put yourself under pressure to feel better straight away.

Try to stay focused on the progress you are making and use any opportunities you can to boost your confidence and self-esteem. This might be by making decisions about your recovery, being as independent as possible or getting out and about as much as you can.

How can emotional changes affect other people in my life?

Relationships can be complex. Our relationships with other people can be affected by how we feel about ourselves.

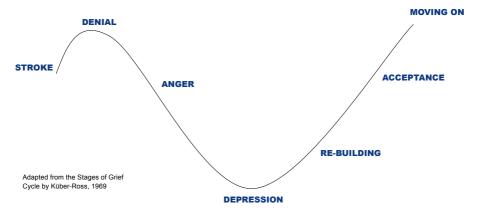
Try to remember that other people may:

- Struggle to understand how you are feeling
- Benefit from hearing your thoughts and feelings
- Have been affected by your stroke too
- Lack the confidence or feel unable to talk about their own fears and feelings
- Be worried about talking about difficult subjects in case they upset you

WHAT CAN I DO TO HELP MYSELF?

A stroke can bring uncertainty, questions and worries with it but there are things you can do to help yourself and find ways to come to terms with what has happened to you. Finding some level of acceptance of what has happened is an important step in being able to move on. However, it is likely that you will go through many emotions before you are able to start coming to terms with your stroke

The diagram below shows the common reactions that people go through after a major life event, such as a stroke, before they come to some level of acceptance of what has happened and are able to move on.



Denial: "this can't be happening to me..." Denial is a way of dealing with the shock of what has happened. It is your body's way of trying to protect yourself by pretending that whatever is happening is not real.

Anger: "why me..., it's not fair..." Anger is a normal and appropriate reaction to what has happened. However, anger is often directed at those closest to you and you may need help to channel your anger in the right way.

Bargaining: "if only..., or 'what if..." After a stroke, some people will do anything to go back to how things used to be. Often they try bargaining (usually with a 'higher power'), for example "I'll do anything if you give me back the movement in my arm". This usually passes fairly quickly as you realise that no amount of bargaining will alter the situation.

Depression: "what's the point...?" Depression is the lowest point of the cycle and can be an ongoing battle as your condition changes. Again, it is quite normal to feel low and feel a sense of loss or regret. But this stage can make it difficult for people to think about self care and their future.

Re-building: "I can't fight this so I may as well prepare for it". This is when you start to turn the corner. You might begin to find out more about your condition and how you can start to manage it. You might start to consider your options and reach out to others for help and support.

Acceptance: Acceptance is often confused with being 'all right' or 'OK' with what has happened. This is not always the case. It is about accepting the reality of what has happened and recognising your 'new normal'. Finding acceptance may just be having more good days than bad days. Acceptance only happens when you can see yourself as you are now and not as you used to be. It is a really important stage in realising that life has changed and you can move on and start making plans for the future.

Relapse: It is important to note that the process is not linear. You may not go through every stage or you may go through the same stage more than once.

Everyone is different and will go through the stages in a different order or will spend a different amount of time in each stage. There is no right or wrong. Remember moving between these emotions is quite normal. The only time for concern is becoming stuck in one of the stages – especially anger or depression. If you are stuck in one of these stages, consider speaking to someone you trust, or a healthcare professional.

Try to set goals for yourself

Setting goals can help you to stay positive and recognise your achievements. It may not be suitable for everyone. But used in the right way and at the right time, goal setting can help you to focus on what you need to do to continue your recovery and come to terms with life after stroke.

If you are going to try it, make sure to set yourself small goals at first. It might help to discuss this with a healthcare professional as they will be able to make sure you are being realistic. For example, your goal might be to walk for 5 minutes a day for the first week and to build this up by 5 extra minutes each week. It is much better to set small steps which will eventually lead to improvement. Keep track of the progress you make.

Goal setting may not be suitable for people who have severe memory problems or who have limited insight into their problems. If you have any concerns speak to your doctor or stroke care team.



GOAL SETTING PLAN

An example of a goal setting plan:

HE	re a	m I j	just	now	?	L	Date.		
I	2	3	4	5	6	7	8	9	10
y a	ctio	n lis	t				В	y wh	en
ow	am	I do	ing?			L	Date.		
I	2	3	4	5	6	7	8	9	10
	y a	y actio	y action list	y action list ow am I doing?	y action list B war I doing? Date.	y action list By whomage by am I doing? Date			

Ask for help

Don't be afraid to ask for help if you need it. This might mean speaking to your doctor, a stroke specialist or a helpline. It could be asking for practical help at home such as a cleaner or help with shopping. If you don't think you are getting the right support call our Advice Line nurses on 0808 801 0899 or email adviceline@chss.org.uk.

Talk to someone

Talking about how you are feeling with someone who understands can really help. This may be a family member, a clinical psychologist, a counsellor or a therapist. Try to keep communicating with those around you so that you don't bottle things up. Bottling things up will only make the emotional problems bigger and harder to deal with.

Talking about how you are feeling can be more difficult if you have communication difficulties after your stroke. It can feel very frustrating or even impossible to try to talk about your feelings if you have a communication difficulty such as **aphasia**. You may want to explain how you feel but not be able to.

A speech and language therapist can help you to find a way that works for you. Other things that can help with communication difficulties include group therapy and support, learning new communication techniques, and specially-adapted devices and computers.

APHASIA FRIENDLY RESOURCES

Your Stroke Journey (Part I Recovering in Hospital and Part 2 **Recovering at Home)** is designed for people who have had a stroke and have aphasia.





To view, download or order these resources, go to: www.chss.org.uk/publications or call the Advice Line nurses on 0808 801 0899.

Some people find that going to a support group really helps them come to terms with the effects of a stroke-it gives you the chance to meet others who have had a similar experience and to find out how they have coped.

> "Meeting and talking with other stroke survivors has really helped me. It's great to be part of such a friendly positive group."



Chest Heart & Stroke Scotland has a number of support groups for people affected by stroke, including their carers. To find out if there is a support group near you, contact the Advice Line nurses on **0808 801 0899** or **email** adviceline@chss.org.uk.

Be informed about your condition

Finding out the information you need and talking to people to get answers to your questions will help you feel more in control of your situation. Understanding what has happened to you, and why, means you can take steps to reduce your risk of another stroke. Being informed will also help you to find the support you need, whether it is emotional or practical help that you are looking for.

Know what skills and information will help you live better

Depending how your stroke has affected you, you may have to learn new skills or relearn old skills. Your stroke team will help you with the practical skills but talking to people about how you are coping and feeling will help you focus on what else you need to live well.

Support groups can also help with this. Many of these groups offer the chance to learn and practice skills to help you stay well. These skills might include exercise and rehabilitation techniques or communication skills. Learning techniques such as relaxation and mindfulness can also make a big difference to your quality of life. There are lots of books, websites and online resources that can teach you about relaxation techniques. There are also courses and groups that can help you.

Don't be too hard on yourself

Dealing with the emotional changes that often happen after a stroke takes time and can be difficult. Take it easy on yourself and don't expect too much too soon. Try not to be selfcritical. There is a lot to cope with so don't feel embarrassed about how you are feeling. Be as honest and open as you can with the people around you. They will want to help but won't be able to unless they know how you are feeling and how they might be able to help.

It is likely you will have good days and bad days. This is normal and you need to pace yourself. There are limits to how much you can achieve in any one day. Stop before you get tired and make sure you have plenty of rest time. Don't be too hard on yourself on bad days. There will be days when everything goes as planned and you feel full of energy and days when everything seems to go wrong. The important thing to remember is that the bad days will pass.

Learn to relax

Learning how to relax is a really good way to cope with feelings of stress, worry and anxiety. Being able to relax will help make a difference to your mood and your energy levels. There are also a number of good resources available on relaxation techniques on the internet. See the Useful Resources at the back of this booklet for more information on where to find these.

Express yourself

When people experience major life changes, they often want to tell someone how they feel. However, sometimes it can be hard to talk about your emotions and feelings for fear of being judged, rejected or giving the wrong impression. This is when finding another way to express yourself and your feelings, such as writing, can be helpful. Writing can also help to put your thoughts in order and bring about a new level of insight and understanding about your own feelings. You could use a laptop or pen and paper, whatever works for you. And remember you do not need to show anyone what you have written. Other ways of expressing yourself include painting, drawing or singing.



Keep in touch

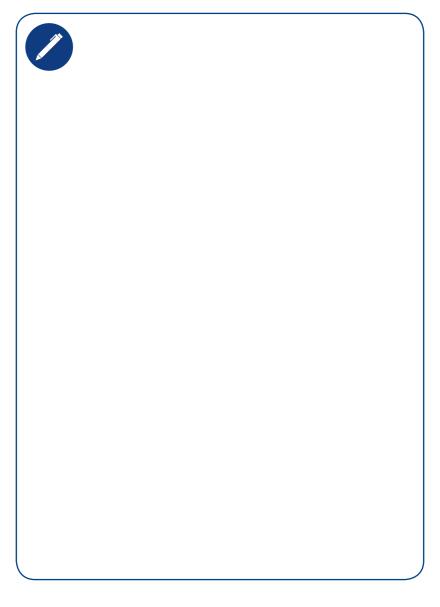
Try to stay in touch with family and friends by encouraging them to visit, or if you can manage it, by taking trips out with them. It can also help to connect with others who can relate to your situation.

This can feel daunting but meeting new people can be hugely helpful for sharing experiences. There may be local community groups in your area where you can share experiences and get professional support.

Tips for coping with difficult feelings

- Look after yourself. Make sure you eat, sleep and, if possible, exercise regularly.
- Take one day at a time.
- Walk away or step back from the situation that is affecting you and take time to think.
- Accept offers of help or ask others for help if you need it.
- Try to keep your social life active.
- Work out what makes you happy and plan ahead to do things you enjoy.
- Try to find time every day to relax.
- Keep a diary.

Explore what works for you. Write down here what helps you to manage difficult feelings. You can use this to work out the best strategies to help you cope.



WHAT HELP AND SUPPORT IS AVAILABLE?

There is a lot of help and support available as you come to terms with your stroke. If you are worried about how you are feeling and how you are coping, then speak to your doctor or a member of your stroke team. They can help you to find the best support for you. Emotional problems can be easily missed as they are not obvious unless you let people know about them. Be open and honest so you can get the support you need.

There are a number of treatments and therapies that can help you, depending on what support you need.

Treatments and talking therapies

Talking about your problems is not always easy. Some people find they cannot talk to family members about how they really feel. You might find it easier to open up to a friend, or to a stroke nurse or therapist who is not so emotionally involved. Your doctor may recommend talking therapy. This gives you the chance to talk about your feelings and problems with a clinical psychologist, counsellor or trained therapist.

Talking therapies can help you deal with and develop ways to cope with your thoughts and feelings. Therapists may work with you one-to-one, with you and your partner or family, or in group sessions.

If this is something you think would help you, speak to your doctor about options in your area. If you decide it is right for you, make sure you let the therapist or counsellor know if you have poor concentration or fatigue. If you have memory or communication problems, ask for a written copy summarising the sessions and any actions to be taken.

You may be referred to your mental health team for more help if your doctor feels it is necessary.

What are my options?

Counselling allows you to talk about various aspects of your life and feelings that are causing you distress. Counselling can help you explore difficult feelings, understand them more and find ways to cope with them. It is important to remember that counselling does not give you direct advice but simply helps you to explore the issues and feelings that are affecting you.

Cognitive Behavioural Therapy (CBT) is a type of therapy that helps you change the way you think (cognitive) and behave (behavioural) so that you can look at your situation in a more helpful way. It focuses on how your thinking and behaviour are connected and explores ways to improve your current state of mind. Telephone and face-toface CBT counselling services are available and usually need a number of sessions over a few weeks.

Taking therapies and counselling services may be available through the NHS in your area. You should speak to your doctor about what your options are or call our Advice Line nurses for more information. Your GP may be able to access an NHS stroke clinical psychology service and refer you to see a clinical psychologist expert in supporting people living with stroke. Such services are not available in all health boards in Scotland.

You may need to wait to see a therapist. If you are finding it difficult to access the service you want through the NHS, you might want to think about private therapy. You can find a private therapist through:

- The British Association for Counselling and Psychotherapy (BACP), which has a 'find a therapist' directory of registered and non-registered therapists. The BACP also has guidance about finding the right therapist for you.
- The British Association for Behavioural and Cognitive Psychotherapists (BABCP), which has a register of accredited CBT therapists.

If you are struggling with communication difficulties after your stroke, then your speech and language therapist can help you to find the support you need.

Medication

Some medicines can help you deal with your emotions. These include antidepressants. Antidepressants balance the levels of certain chemicals in the brain, improving your mood. If you are prescribed antidepressants they make take a few weeks to take effect fully. Be aware that they don't work for everyone and can have side effects. There are many different antidepressants and it might be a case of trial and error to find the one that best suits you. If you feel that antidepressants might help you, then talk to your doctor in the first instance. You can have a combination of medication and talking therapies.

How can CHSS help?

CHSS offers a range of support for people and their families, living with the effects of a stroke.

Stroke Services

We provide support for people who have difficulty with communication and physical and everyday tasks after a stroke. The services provided may differ depending on where you live in Scotland. Our aim is to help people who have had a stroke and their families get their lives back on track. Support is provided through one-to-one support or in a small group. In some areas of Scotland, CHSS can provide support from a stroke nurse or occupational therapist as you leave hospital after a stroke. Your hospital stroke care team will need to refer you for this service if it is available in your area. Contact the Advice Line nurses for more information.

Support Groups

Hearing how other people are coping after a stroke can be a life-line for some people. CHSS has stroke support groups all over Scotland. To find out if there is a stroke support group in your area, call the Advice Line nurses on 0808 801 0899, email them on adviceline@chss.org.uk or see our website at www.chss.org.uk.

Advice Line

For confidential, independent advice on all aspects of life after stroke, call the CHSS Advice Line nurses on 0808 801 0899 or email adviceline@org.uk. The Advice Line is open Monday-Friday 9.30am to 4.00pm. All calls are FREE from landlines and mobiles.

Health Information

CHSS have a range of booklets and easy-to-read 'essential guides'. To see the full list of guides and other resources and to order, view or download them, go to: www.chss.org.uk/publications or call the Advice Line nurses for more information on 0808 801 0899.

Selfhelp4stroke.org

This is an online resource to help people who have had a stroke. It includes sections on keeping well, being active, emotional support and coping with setbacks. See www.selfhelp4stroke.org.



Stroke4carers.org

This is an online resource for carers of people who have had a stroke. It provides practical advice and tips for carers including support, advice for caring at home and information on money and available benefits. See www.stroke4carers.org.

For information on any of our services across Scotland, contact the Advice Line nurses on 0808 801 0899 or email adviceline@chss.org.uk.

USEFUL RESOURCES

Chest Heart & Stroke Scotland

Rosebery House, 9 Haymarket Terrace

Edinburgh EH12 5EZ

Tel: 0131 225 6963

www.chss.org.uk

Advice Line: 0808 801 0899 (Mon-Fri 9.30am-4pm)

E-mail: adviceline@chss.org.uk

Chest Heart & Stroke Scotland supports people in Scotland affected by chest, heart and stroke conditions. We do this by working to ensure there is help and support in every community for anyone who needs it.

Breathing Space

www.breathingspace.scot

Tel: 0800 83 85 87

Weekdays: Mon-Thurs, 6pm-2am

Weekend: Fri 6pm-Mon 6am

Breathing Space is a free confidential phone and web-based service for anyone who is experiencing low mood or depression.

Steps for Stress

www.stepsforstress.org

A simple guide to stressing less and enjoying life more.

Moodjuice

www.moodjuice.scot.nhs.uk Offers information and advice to those experiencing troublesome thoughts, feelings and actions.

Living Life to the Full

www.llttf.com

The Living Life to the Full course is a life skills course that aims to provide access to high quality, practical and userfriendly training in life skills.

British Association for Counselling & Pyschotherapy (BACP)

www.bacp.co.uk

The UK's professional body for accredited therapists and counsellors. The BACP has a 'Therapist Directory' section on their website with local contacts and their areas of speciality.

Counselling and Psychotherapy in Scotland (COSCA)

www.cosca.org.uk

Scotland's professional body for counselling and psychotherapy. The website has a register of accredited counsellors and psychotherapists in the 'Find a Counsellor' section.



Chest Heart & Stroke Scotland welcomes your comments and feedback on this resource to help us to develop the best information for you and others who have had a stroke.

If you have any comments regarding this booklet or any of our other publications you can contact us through:



www.chss.org.uk



healthinformation@chss.org.uk



Rosebery House, 9 Haymarket Terrace Edinburgh EH12 5EZ

PERSONAL STORIES

We would also like to hear from you if you would like to tell us about your experience of living with a stroke, or of caring for someone with a stroke.

Chest **Advice Line** Heart & Nurses Stroke **Scotland**



For confidential help, support and advice, call our specialist nurses or visit

www.chss.org.uk

OUR **PUBLICATIONS**

We hope this information has been useful to you.

Our publications are free to anyone in Scotland who needs them.

To view, download or order any of our resources, visit **www.chss.org.uk/publications**

If you'd like more information about our publications, please contact our Health Information team:



healthinformation@chss.org.uk







Chest Heart & Stroke Scotland is a Scottish charity. Our ambition is to make sure that there is no life half lived in Scotland.

After a diagnosis of a chest or heart condition or a stroke, many people experience fear and isolation and struggle with the impact on their lives. **Chest Heart & Stroke Scotland** won't stand for that. The care and support we deliver every day ensures everyone can live the life they want to.

We offer our resources free of charge to anyone in Scotland who needs them. To help us to continue to do this, and to help provide vital services to people in Scotland affected by chest, heart and stroke conditions, you can donate at:

www.chss.org.uk/supportus/donations

CONTACT US

For confidential advice, support and information call the CHSS Advice Line nurses on:
Freephone 0808 801 0899 or email adviceline@chss.org.uk

Head Office

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www.chss.org.uk

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