

COMING TO TERMS WITH A STROKE



ESSENTIAL GUIDE

This Essential Guide is about coming to terms with a stroke.

It explains:

- How to find out more about your stroke.
- Some common thoughts and feelings after a stroke, and how to manage them.
- What you can do to help your recovery.
- Services, medications, and support available to you in Scotland.

The impact of stroke

Even besides the symptoms, a big medical event like a stroke can have all sorts of impacts on your life.

It may be difficult to come to terms with what has happened to you, or to make changes in your life that might be needed afterwards. You are also likely to have questions and anxieties about what has happened, and what comes next.

All of this is part of the process of recovery for most people, and there are things you can do to come to terms with the changes and feel more like yourself going forwards.

This booklet aims to offer some support with this process, and help you find answers to common questions after a stroke.



Common questions

After a stroke, most people have questions.

It can be hard to understand the answers when you first hear them. You get a lot of information all at once, when you are not in a state to process it. You may also find that the answers use language that is clinical, scientific, or otherwise difficult to understand.

Remember – it is always okay to ask the same question more than once, or to ask it to multiple people! The most important thing is that you understand what has happened to you as well as possible.

CHSS has a range of booklets and factsheets which may help you to understand the medical aspects of what has happened to you. Find them online:
www.chss.org.uk/resources-hub



The following questions can be helpful to ask while in hospital:

- Where in my brain was the stroke?
- Do you know what caused it? How can I reduce my risk in the future?
- What were the results of my assessments? Which symptoms should I look out for?
- Will I need to take medication after I leave hospital? How often, and for how long? What side effects should I watch for?
- Who is the lead on my stroke team? Who should I speak to if I have questions after I leave hospital?
- Which services do you recommend?
- Does the stroke team know who to contact if I am unavailable?
- What should I do if I notice new symptoms or if my symptoms seem worse?

The following questions can be helpful to ask after leaving hospital:

- Who can I call for support if there are problems? Which professionals? Which friends or family members?
- Can someone stay with me? (Either a friend/family member, or a professional)
- How often do I need follow-up appointments?
- Which rehabilitation services do you recommend?
- What support is available in my area? Can I get support with financial needs, disability accommodations, etc?
- How can I safely exercise?
- What foods and drinks are safe, healthy, and easy for me to prepare?
- What exercises can I do at home to improve my mobility, speech, etc?

The following questions can be helpful to ask yourself:

- How do I feel about what has happened?
- Who can I speak to about this?
- Are there people already in my life who can support me, or should I look for outside support from a carer, support group or therapist?
- What can I still do? How can I build on that?
- How can I adjust my approach to this task to make difficult activities easier?
- Do I know how to ask for help if I need it? Am I prepared to ask for help?
- Do I understand what the health team are telling me? If not, what can I ask to get the information I need?
- Am I using all the tools available to me?



Accepting uncertainty

It is important to know that some aspects of stroke recovery are unpredictable, and some questions cannot be answered. This does not mean information is being withheld from you - some things are just unknown! For example:

- **Will I have another stroke?**

You can reduce or increase the risk of another stroke, but nothing will make it either impossible or certain.

- **How long will recovery take?**

Recovery is a personal, unpredictable process. There is no single timescale for recovery - but with hard work and patience, progress is likely.

- **Are these all my symptoms?**

It is possible, though unlikely, for new symptoms to emerge some time after your stroke. You may also discover issues when trying new activities.

How to find out more

Finding out the information you need will help you feel more in control of your situation, and to find the support you need.

Ask your stroke team. Your doctors and other health workers should be your first call, as they know your case best.

Seek out charity support. Look at the end of this booklet for organisations you can contact for health and support, including CHSS.

Ask other stroke survivors. You can find support groups in person or online. It can also help to read books or listen to podcasts by people who have had a stroke before.

Look online - but be careful! There is a lot of false information online. Be wary of anything that is trying to sell you anything. Look for sites with reputable sources like the NHS or stroke charities.



Feelings after a stroke

It is vital to be ready for the strong emotions that often follow a stroke, and to understand what you're dealing with.

Ask yourself **which of the following common feelings resonate with you**, and why you might feel that way:

accepting	fear	positive
angry	frustrated	rattled
anxious	grateful	relieved
cared-for	grief	resigned
confident	guilty	sad
curious	helpless	scared
demoralised	homesick	self-pitying
depressed	hopeful	stressed
denial	impatient	tense
distressed	lonely	uncertain
doubtful	miserable	upset
embarrassed	motivated	weak
exhausted	overwhelmed	worried

Why do I feel like this?

A stroke is a huge life event. You will be faced with a lot of information and uncertainty at a challenging time. The symptoms can be tiring or otherwise hard to deal with emotionally.

Stroke can also directly affect your emotions, making it hard to manage your feelings or causing unusual emotional responses. For instance, you may cry, laugh, or swear unexpectedly. This is called **post-stroke emotionalism** or **emotional lability**.

Your life may change in big ways, and you and the people around you may struggle with shock, fear, and uncertainty. Even the most resilient people will struggle with this kind of stress. It is normal to experience a lot of strong emotions, even contradictory ones.

Whatever you are feeling after a stroke, it is valid to feel it. Be gentle with yourself, and give yourself time to heal.

Grief and loss

Changes after a stroke can be a kind of bereavement - a loss of the life you used to have. After a stroke, many people deal with feelings of grief or loss. These feelings are normal and healthy.

The best way to deal with grief after a stroke is to recognise what you have lost and be honest with yourself and others about how you feel. As time goes on, these feelings usually become easier to manage.



The stages of grief

You may have heard of “five stages of grief”. While this is not a scientific concept, it can be a good way to understand common feelings after a traumatic health experience or loss.

Despite the name, these “stages” often come in a different order, or multiple stages at the same time.

The stages of grief are:

Denial. Many people struggle to believe what has happened to them, try to ignore the situation, or are unable to accept that there are things they can no longer do.

Anger. It is common to feel angry, frustrated, or resentful towards your own body, the people around you, or even at the universe or at God for letting this happen.

Bargaining. Believing that you can guarantee your recovery by doing (or not doing) specific things, giving you a false sense of control. You might try to bargain with yourself, with the doctors, or with God or another spiritual force.

Depression. Low mood, difficulty finding pleasure in things, and a sense of despair are common after any medical crisis, especially one with a long recovery period.

Acceptance. In time, you can come to understand and accept what has happened.

Relationships

A stroke can affect relationships in many ways:

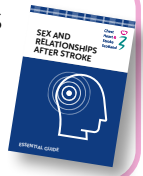
- It may be difficult to express what you have experienced, how you feel about it, and what you are going through, which can make you feel lonely and isolated.
- You may be less able to do things you used to do, and need to readjust your expectations of yourself and each other.
- The people around you may be under new pressures as a result of your stroke, especially if they are caring for you.
- Your stroke may affect your ability to communicate with the people around you.
- Some people find it difficult to manage and control their emotions after a stroke. You may lash out at people or respond to them in awkward or embarrassing ways.

- You may struggle with sex and other physical expressions of affection. There are ways to deal with these difficulties, but it will take time to readjust.

In general, it is important to know that most relationships can be maintained after a stroke, but it may take time, effort, and readjustment to rebuild your relationships.

The most powerful tool in keeping healthy relationships after a stroke is **honest communication**. Being open about your feelings, struggles, and limitations, and encouraging the people around you to do the same, allows you to recognise what you need from each other and to find a way to reach that goal.

For additional advice on relationships (including family relationships and friendships), see our booklet on **Sex and Relationships After Stroke**.



What can I do to help myself?

There are things you can do to help yourself, manage your emotions, and give yourself a level of control over the situation.

These include:



Setting goals for your recovery



Asking for help



Talking about your feelings



Being gentle with yourself



Learning to relax



Expressing yourself clearly



Keeping in touch

Setting goals for recovery

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 your recovery and come to terms with life after stroke.

Make sure to set yourself small goals at first, and build on them slowly over time.

It might help to discuss this with a healthcare professional who can help to make sure you are being realistic and not overstretching yourself.

It is better to set small steps and move slowly towards your goals. Keep track of your progress.

Goal setting may not be suitable for people who have severe memory problems or who are unclear about their problems. If you have any concerns, speak to your doctor or stroke care team.

Asking 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 also be asking for practical help at home such as a cleaner or help with shopping.

It can be difficult to ask for help, especially if you are used to being independent or if you usually take the role of a carer or supporter in your relationships.



Remember: you are not helping anyone by suffering in silence! Most people want to help, and will feel better if you give them the opportunity to do so.

If you don't think you are getting the right support, call our Advice Line on **0808 801 0899** or email **advice@chss.org.uk**.



Talking about your feelings

Talking about how you are feeling with someone who understands can really help. This could be a family member, a clinical psychologist, a counsellor or a therapist.

Try to keep communicating with those around you. Bottling your feelings up will only make the emotional problems bigger and harder to deal with.

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

It can be frustrating and difficult to talk about your feelings if you have a communication difficulty like aphasia. These difficulties can be managed with support.

Find more information and support in our easy-read booklet on **Aphasia**.

Being gentle with 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 self-critical. You are dealing with something that is extremely difficult and there is no "right" way to cope or heal. Remember: all you can do is your best, and that is enough.

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, even on days when you feel good.

There will be days when everything goes as planned and you feel full of energy, but also days when everything seems to go wrong.

The important thing to remember is that the bad days will pass, and over time, the good days will get more common.

Learning to relax

Relaxing will help improve your mood and energy levels. It is an important tool for managing stress, anxiety, and low mood.

Some helpful relaxation techniques include:

- Meditation and mindfulness exercises.
- Using adult colouring books.
- Listening to music or white noise.
- Yoga, pilates, tai chi, and similar exercises.

You can ask your GP or stroke team for support in finding relaxation techniques and mental health support.

There are also resources available online to help with relaxation techniques. Many of these are free, so do not feel that you have to pay for them! You can just as easily learn relaxation techniques through YouTube tutorials, free webpages, and mental health organisations.



Expressing yourself

It is important to express how you feel, but sometimes it can be hard to talk about your emotions and feelings in words. Finding other ways to express yourself and your feelings can be helpful.

Writing down thoughts and feelings can help to order your thoughts, making them easier to understand. Remember - you do not need to show anyone what you have written unless you want to!

Creative writing - such as poetry or fiction - can make it easier to approach your feelings and experiences.

Drawing and painting can help to express yourself more abstractly. Try to let go of the idea that it should look "right" - this isn't about artistic skill, but letting your feelings out.

Singing is often easier than talking, letting you express your emotions more fully.



Keeping in touch

Isolation and loneliness are often the most dangerous feelings in the wake of a stroke. On the other hand, friendships and human contact are known to improve resilience and make recovery more effective.

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. Be realistic about what you can manage - you may only be able to socialise for short periods at a time, but that is still better than nothing!

It can also help to connect with others who can relate to your situation. This can feel daunting, but meeting new people with similar experiences can really help.

There may be local community groups in your area where you can share experiences and get professional support.



Ongoing treatment

You may need treatment after your stroke, either to reduce your risk of another stroke, to deal with your symptoms, or to help build up your strength and ability.

This might include:



Occupational therapy



Speech and language therapy



Physiotherapy



Medication such as statins



Pain medication



Massage therapy



Counselling and therapy

Seeking medical help

It is important to know who to speak to if you are having trouble coping after your stroke, or if you have questions about your treatment or what happened to you.

Your stroke team should be your first port of call if you have any concerns about your health or recovery post-stroke. If you are unable to contact them, you can also speak to your GP or pharmacist, who may be able to direct you to other local services.

It can be helpful to prepare your questions in advance before medical appointments.

For advice on how to do this and which questions are important to ask, see the CHSS factsheet on **How to Make the Most of a Visit to your Doctor**



Counselling and therapy

Talking about your problems is not always easy, but it is important. If you are struggling, your doctor may recommend talking therapy.

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

Let the therapist or counsellor know if you have issues with focus, memory, communication, or fatigue. You can also ask for written notes to recap the sessions.

If you think talking therapy would help, speak to your doctor about options in your area. You may be referred to your mental health team for more help if your doctor feels it is necessary.



Support groups

Support groups can be a great place to meet people who have been through the same things as you. This makes it easier to talk about your feelings and experiences, and can help you to find out about how other people cope and manage their symptoms.

You can attend support groups in person if they are available in your area. There are also support groups online. Online groups might meet in video calls, or talk through text forums.

CHSS has stroke support groups all over Scotland. To find one in your area, call the Advice Line on **0808 801 0899**, email **adviceline@chss.org.uk**, or search our groups online at **www.chss.org.uk/services/peer-support-groups**

You could also ask your stroke team or search “**stroke support group Scotland**” online.

How we can help you

CHSS offers a range of support for people (and their families and carers) living with the effects of a stroke. Contact the Advice Line for more information on any of the below.

Stroke Services

In some areas of Scotland, CHSS can provide support from a stroke nurse or occupational therapist when you leave hospital. Your hospital stroke care team will need to refer you for this service.

Advice Line

Free, confidential, independent advice on all aspects of life after stroke.

Selfhelp4stroke.org

An online resource to help people who have had a stroke. Access it online:

www.selfhelp4stroke.org

Stroke4carers.org

An online resource which provides practical advice and tips for carers of someone who has had a stroke. Access it online:

www.stroke4carers.org

Kindness Volunteers

If you are struggling with loneliness and isolation, you may be able to sign up for our Kindness initiative. You will be matched with a volunteer, who will call you regularly to chat.

Financial Support

CHSS can offer financial advice and support to those affected by chest, heart and stroke illness. Email **personalgrants@chss.org.uk** or call **0131 225 6963** to find out more.

Health Information

We have a wide range of factsheets and booklets like this one, available online at **www.chss.org/resources-hub**. You can also order free print booklets through this link.

Advice and support

Besides your health team, friends and family, you can find advice and support through:

Chest Heart and Stroke Scotland

Call 0808 801 0899 to speak to one of our trained Advice Line practitioners.

www.chss.org.uk

Email: adviceline@chss.org.uk

Breathing Space

A free, confidential phone and onlineservice for anyone struggling with low mood.

www.breathingspace.scot

Tel: 0800 83 85 87

COSCA

A register of psychotherapists and counsellors in Scotland, which can help you to find a private counsellor/therapist near you.

www.cosca.org.uk

Tel: 01786 475140

Email: info@cosca.org.uk

Disability Information Scotland

A hub for information on accessing more generalised disability support, like mobility aids, accessible spaces, legal rights, and financial support.

www.disabilityscot.org.uk

Helpline: 0300 323 9961

Text: 0798 436 7599

Email: info@disabilityscot.org.uk

Living Life to the Full

A range of free mental health self-help courses, with worksheets and reading lists, written by a psychiatric professor at the University of Glasgow.

www.lltff.com

NHS Inform

The central hub for information from NHS Scotland, covering a wide range of conditions, symptoms, and services.

www.nhsinform.scot

Our publications are available for free to anyone in Scotland who needs them. Go to www.chss.org.uk/resources-hub for all our resources, including other Essential Guides in this series.

For free, confidential advice and support from our **Advice Line nurses**, call: 0808 801 0899 (Mon-Fri 9.30am-4pm), text: NURSE to 66777 or email: adviceline@chss.org.uk.

Across Scotland, over one million people – that's one in five of us – are living with the effects of a chest, heart or stroke condition. We are here to help everyone who needs us. But we need your support to do this. Go to www.chss.org.uk/supportus to find out how you can help more people in Scotland.

If you would like this resource in an alternative format, please contact our Advice Line nurses.

**Chest
Heart &
Stroke
Scotland**



NO LIFE HALF LIVED

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