



Chest
Heart &
Stroke
Scotland



STROKE CARER'S GUIDE



ESSENTIAL GUIDE

This Essential Guide is about caring for someone who has had a stroke.

It explains:

- Who is a carer and what support carers can receive.
- What to expect after someone you know has had a stroke.
- Advice on managing common symptoms of stroke.
- How to take care of yourself and look after your own health as a carer.

Am I a carer?

If you are helping someone in your life with a medical condition, then you may be considered as an **informal** or **unpaid carer**.

This might mean helping with **medical needs**, like helping with therapy or appointments.

It might mean helping with **practical needs**, like housework, transport, or personal care.

It might also include providing **emotional support** and being a shoulder to cry on.

If you are regularly spending time helping with any of these things as a result of a person's stroke or other illness, even if you do not live with that person, you may be considered an informal carer.

For more information on being an informal carer and what help and support you can get, find our booklet on **Carer's Rights** online for free at **chss.org.uk**

What to expect after a stroke

Besides direct clinical symptoms of a stroke, many people also struggle with:

- **Emotional responses.** A stroke is a traumatic event, and many people experience anxiety, low mood, and fear.
- **Difficulty adapting** to their new limitations and symptoms, which often mean a lot of changes to daily life.
- **Difficulty accepting help.** Many people who were independent before their stroke struggle with asking for, or receiving, help and care even if they need it.
- **Social isolation and loneliness.** Many stroke survivors struggle to return to their usual social activities, or to explain to others what they are going through.

- **Changes in relationships.** This applies to friendships, family, and romantic relationships. A stroke often changes how people are able to relate to others, and adjusts the balance of existing relationships.
- **Embarrassment.** People may experience symptoms that they find embarrassing, such as facial drooping or difficulty talking. It can also be embarrassing to need help with personal care and hygiene.

It is important to remember that all of these can affect you as a carer, too. Becoming a carer is likely to affect your life in many ways, and it is normal to have some difficulty adapting to begin with. Watching someone you love go through a traumatic event can also be traumatic for you.

Remember - you can't pour from an empty cup! Take care of yourself first, and look for support if you can.

Common symptoms after a stroke

Stroke symptoms vary a lot between people. Common symptoms of stroke include:



Loss of mobility. Many strokes lead to muscle weakness or paralysis. A person might struggle to walk, lift things, or even to eat and drink.



Difficulty communicating. Stroke can cause aphasia (damage to the parts of the brain that control language), and muscle weakness can make it hard to speak or write.



Cognitive or or sensory changes. A stroke can affect how people think or experience the world.



Bladder or bowel incontinence. A stroke can affect a person's ability to control bodily functions.



Emotional dysregulation, or a difficulty controlling how and when emotions are expressed. This might mean someone's emotions are stronger, or that they have unusual or inappropriate reactions (e.g. laughing when something is sad)



Loss of vision. After a stroke, there may be changes to someone's sight, leaving them blind or partially-sighted.



Pain or changes in feeling. A stroke can change how people experience all kinds of sensation, and can cause chronic pain.



Tiredness or fatigue, to an extreme level which makes it difficult to function day-to-day.



Problems swallowing or eating as a result of muscle weakness.

Managing physical needs

When someone has had a stroke, they will often need help with physical activities.

It is important to be careful when offering physical support. Make sure that you are mindful of your own physical limitations and needs, and that you have spoken to health professionals where possible to make sure you know the best way to support them.

Rehabilitation and therapy

After a stroke, rehabilitation should be started as soon as possible. This will usually include physical exercises to be completed regularly, as well as appointments with specialists.

If possible, try to attend these appointments and ask questions about the best ways to support and help with the exercises at home.

Lifting and moving

You should **only** try to move or lift a person if you are fully trained in how to do so safely. Ask a physiotherapist, nurse, or occupational therapist how to do this.

If the person affected by a stroke has a weak arm, you should never lift them by pulling on it, as this can damage the joint. Always be mindful of whether you could be hurting them, and make sure they have a way to tell you if they are uncomfortable.

Swallowing

Many people struggle with chewing and swallowing after a stroke. You may need to help with preparing safe foods. For more information, see our factsheet on **Dysphagia** (available on www.chss.org.uk).

It is also important to be present while someone with swallowing issues is eating or drinking. Check with health professionals what you should do to help if they choke.

Communication

If someone's ability to communicate is affected by their stroke, they will probably be referred to a speech and language therapist (SLT) who will give them exercises to work on.

Practice is important in helping to manage communication after a stroke, so if you can get involved in supporting practice at home, this will be very helpful. Ask the SLT if you are unsure how best to do this.

Bladder and bowel incontinence

After a stroke, some people lose control of their bladder and/or bowels.

Ask the health team for advice if necessary. You may also be able to get support with the costs of equipment like incontinence pads.

When cleaning up incontinence, safety is important. Use gloves if it is more comfortable, and always wash your hands after with antibacterial soap and hot water.

Falls and seizures

Falls are more likely after a stroke. Be aware of this, but do not stop the person you are caring for from being active. You can reduce the risk of falls by ensuring the floor is clear and level, that there are not things around to trip over, and that the person uses a stick or walking frame when needed.

Do not let the person tackle stairs on their own until they have been assessed as capable by a professional.

In rare cases, stroke can also cause epileptic seizures. If this happens, you should **call 999** and seek immediate medical help.



Managing emotional needs

A stroke can affect someone's emotions directly, by damaging the parts of the brain that control emotion. It can also affect emotions indirectly - a stroke is traumatic and the process of recovery can be very difficult.

As a carer, it is important to be supportive and aware of these new emotional needs.

Emotional outbursts

Stroke can affect control of emotions, making it difficult for people to regulate themselves. Stress and frustration can also lead to outbursts of anger or severe low mood.

After a stroke, people may also behave in unusual ways, doing things like crying, laughing, or swearing at inappropriate times. This can be frightening or upsetting for the people around them.

Try to remember that these outbursts are not necessarily personal. Take space if you need to - leave the room if possible, catch your breath, and come back when you are able.

Personality changes

Some people may experience changes to their personality after a stroke. This can be very difficult to understand or deal with. If you are struggling with this, it is important to be open and speak to someone you trust.

Trauma and anxiety

Following a stroke, it is common for people to struggle with fear and anxiety about another stroke. They may also have trauma responses to situations which remind them of their stroke.

Anxiety does not always respond to logic, but it is still helpful to reassure them of what is in place to keep them safe. If you can help them to avoid anxiety triggers, this is also good.

Low mood and depression

Many people experience low moods after a stroke. It is important to validate these feelings, but also to recognise when this may cross into clinical depression.

Common depression symptoms include changes in appetite and sleep, low energy and loss of motivation, difficulty concentrating, and reduced care about one's appearance. If someone is showing these symptoms, and especially if they have expressed a desire to hurt themselves or to stop living, it is important to speak to them and to their health team about your concerns.

Loneliness and isolation

A stroke can often lead a person to withdraw from social activities, and loneliness is common. Where possible, encourage the person you care for to take part in support groups and social activities. It is also very helpful to just be there, listening, and caring.

Taking care of your own emotions

While it is important to support the person you care for with their emotional struggles, your own emotions are just as important. Being a carer does **not** mean that you have to ignore or overlook your own emotional needs to care for someone else's.

All of the emotional difficulties mentioned in the previous pages, apart from personality changes, can also be experienced by you as a carer. It is important to know that this is normal and okay.

Make sure that you have someone to talk to, and that you know how to take care of your own emotional and mental wellbeing.



Taking care of yourself

When caring for someone, it is more important than ever that you look after yourself, too. Caring can be difficult or stressful at times, and it is important that you look after your own mental and physical health.

Some things that may be helpful are:



Joining a support group, carer's centre, or other network for carers who can share your experiences.



Take regular breaks. Try to build time into your schedule that is just for you - a hobby you enjoy, a cup of coffee with a friend, or a walk on your own. This could be during medical appointments, or you could arrange for a friend, family member, or professional carer to watch the person you care for if needed.



Take holidays. You can arrange respite care if needed. These holidays might not involve actually going away - the important thing is to have time off from your caring responsibilities.



Talk to someone - a friend, family member, or counsellor.



Take care of your own health.

Exercise, diet, sleep, and regular health checks can all improve your overall health and make it easier to care for someone else.



Treat yourself. Make sure to build things you enjoy into your plans, as well as things for other people's sake.



Share responsibilities if you can.

Even if you are someone's primary carer, it can take a lot of stress off to know there is someone else to turn to.

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

Befriending Networks

Befrienders are volunteers who can visit or chat with you or the person you care for, to help fight loneliness and isolation.

www.befriending.co.uk

Carers Scotland

A charity supporting carers and campaigning for greater support.

www.carersuk.org/scotland

Tel: 0141 378 1065

Email: advice@carersuk.org

Care Information Scotland

Information on caring and care support.

www.careinfoscotland.scot

Tel: 0800 011 3200

Carers' Trust

A UK-wide charity which works to connect carer's networks and advocate for carers.

www.carers.org

Different Strokes

A charity specialising in helping young stroke survivors and their carers.

www.differentstrokes.co.uk

Shared Care Scotland

Helps you to find/plan respite care or support.

www.sharedcarescotland.org.uk

Tel: 01383622462

Stroke4Carers

An online resource explaining stroke.

www.stroke4carers.org

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.

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