

Chest
Heart &
Stroke
Scotland



STROKE

RECOVERY AT HOME



ESSENTIAL GUIDE

This Essential Guide is about recovering at home after a stroke.

It explains:

- What a stroke is, and some of its symptoms.
- What to expect when you are discharged from hospital.
- Who will be involved in your care.
- Tools to help you manage life after a stroke.
- Where to find out more

For information on the earlier stages of recovery, see our booklet on **Stroke Recovery in Hospital**.

What is a stroke?

A stroke is a medical event where the blood flow to your brain is interrupted - either by a blockage or a bleed. This starves your brain of oxygen, causing brain damage. This can affect all kinds of things, including:

- Your mobility and muscle control;
- Your communication;
- Your thinking, feeling, or emotions;
- Your hearing, vision, or sense of taste;
- Your bladder and bowel control;
- Pain or discomfort;
- Your sex drive, fertility, or menstrual cycle;
- Your energy, fatigue, or stamina.

For more detailed information on stroke, see the Essential Guide on **Stroke**, available at www.chss.org.uk/resources-hub

Leaving hospital

After a stroke, you may have spent a significant amount of time in hospital, and going home may feel scary or confusing.

You should be told well in advance when your team are planning to discharge you from hospital. They should work with you, your family and other people in your life, to make sure that everyone knows what is happening and what comes next.

You should be given a referral to support services after you go home, and follow-up appointments with your stroke team.

You should **not** be sent home without a clear plan for how you will be cared for at home, and who will be involved in your recovery.

If there is anything you are uncertain or unclear about, you have the right to ask your care team. This is true both while you are in hospital, and after you go home.

Before leaving hospital, make sure you and anyone supporting you at home understand:

- Who will pick you up from the hospital, and when.
- Who to contact if you have questions or concerns after you leave hospital.
- What medications or treatments you will take at home, how often, and how to use them (including any side effects).
- Changes or warning signs to watch for.
- Whether you need to arrange a carer or other home support.
- What aids or adaptations you might need in your home.
- How to do any rehabilitation exercises.
- When you need to return to the hospital for a follow-up appointment.
- Where you can find more information about your symptoms and treatment.

What if I need extra care at home?

Most people who leave hospital after a stroke will require extra care for at least some time after they go home.

This can be partially provided by someone in your life, like a friend or family member, but you should also be referred to your local council's home care services.

The level of care the council provides you should be determined by an assessment of what tasks you can and cannot safely do.

This assessment should be done in hospital, but it may be done soon after you go home if you are not in hospital for a long time.

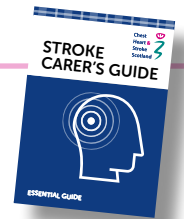
You should not be sent home from hospital until your team are assured that you will get the necessary care and support at home.

Depending on how much care you need and on your financial position, you may need to pay for your care at home.

You may also need to make adjustments to your home to live more independently after a stroke. Speak to your stroke team about what adaptations might be needed. Remember that financial support for aids and adaptations may be available through your local council's Scheme of Assistance.

To find out more about how you can manage paying for care and adjustments, see our booklet on **Financial Support**.

To find out more about caring for a stroke, see our booklets on **Carer's Rights** and **Stroke: A Carer's Guide**.



Community support services

It is likely that part or all of your care at home will be provided through community support services. These could be provided directly by your local government, or through a charity or volunteer organisation. They could also be provided by a private company.

Community support services to help you live more independently could include:

- Help with washing, dressing, and personal care.
- Help with housework and key chores.
- Helping with shopping or providing meals.
- Day to day care.
- Respite care (taking over care from a friend or family member for a short time so that they can have a break).
- Advice on how to access benefits, transport, housing, and/or equipment.

What if I can't go home?

You should be supported to make your home as safe and comfortable as possible for life after stroke. However, in some cases, it may not be possible to make your home suitable for your needs. This might be because of the building itself (for instance, if you live in a top-floor flat without a lift), or because your care needs cannot be met in your own home.

In this case, you may need to move to sheltered housing or residential care. You will have to pay for this, although financial support may be available.

If your care needs assessment shows that you need residential care, you will be given a list of recommendations for suitable supported housing. You can choose from this list or do your own research - but make sure you ask your stroke team whether a service you have found yourself will meet your needs.



Where to get help

Coming home from hospital can be scary, but you do not have to do it alone. You can get support with all aspects of adjusting to your life after a stroke - from medical care and rehabilitation, to emotional support, to help with daily tasks.

There are specific links at the end of this booklet, but some more general examples of where you can go for help include:

Your GP, pharmacist, or stroke team. Health professionals can help you to understand what has happened to you, direct you to services, or advise you on strategies to manage your symptoms and health.

You may also be able to access stroke nursing and liaison services in your community. They can help you to adjust to your symptoms and advise you on next steps

Your friends and family. Loved ones can listen to you and help you to talk through your feelings and worries. They may be able to help with daily tasks, to accompany you to appointments, or support you in other ways.

Local community groups. Many communities have community networks for things like transport, befriending, or helping with chores. These can help you get support while staying connected to your community.

Support groups. A stroke support group, online or in person, can be a great way to connect with people who have had similar experiences. You can share experiences and feelings, and exchange coping strategies.

A psychotherapist or counsellor. Especially if you can find a therapist who specialises in disability or stroke, therapy can make a lot of difference to your mental health and overall wellbeing.

Explaining what has happened to you

When you leave hospital, it can be difficult for you, and people close to you, to respond to questions and concerns about what has happened. You may still be trying to understand it yourself!

This booklet cannot tell you how to manage every conversation - it will depend on who you are talking to and when. However, there are a few rules of thumb which can make it easier to know what to say after a hospitalisation.

Keep it simple. You do not have to give every detail - if people want to know more, it is their responsibility to ask the specific questions.

Keep it comfortable. You do not have to tell people anything you would rather keep to yourself.

Know what you need. People may want to help, and this is easiest to manage if you already have an idea of what would be helpful. This will take time to work out, and your needs may change, but it can be useful to sit down and make a list of things that would be helpful for you.

Talk it out. Talk through what has happened with others who were with you in hospital, such as friends and family. This can help all of you to understand it better, and give you a clearer idea of what to say to others.

Remember: this is about you. While a stroke can be very difficult for people around you, it is ultimately your health and your life. Nobody else gets to decide what your priorities in recovery are, or tell you how to feel. You do not have to sacrifice your own recovery or emotions to make anyone else feel comfortable. If they are uncomfortable, they should be able to walk away.

Asking for help

Many of us are reluctant to ask for help, especially with things we feel we should be able to manage on our own. This can be especially difficult if you are used to being in a responsible role - for instance, if you are a parent or care for a loved one.

However, it is important to ask for help when you need it, and not to wait until you are desperate. The longer you wait to ask for help, the worse the situation can become, and you may need more help as a result.

Asking for help is not imposing on anyone. They can always say no (and if they do, you can ask someone else).

After a stroke, people around you will often be looking for ways they can help. Asking for their help is likely to be welcome, as most people prefer to feel like they are making things better for the people they care about.

Do remember, though, that you do not have to accept **every** offer of help! If you know that what someone is offering will not actually be helpful (or even make things harder), you do not need to take that offer. It can make it easier if you suggest another way that they can help.

The more specific you are with your requests, the more likely it is that you will get the help you need.

Ask for help with small things. This makes it easier to ask for help with the bigger things.

Letting people support you is one of the best ways to manage your recovery. Remember, you do not need to do everything on your own!



Treatment and rehabilitation

Your medical treatment will not end when you leave hospital. It is important that you know what is expected of you in managing your treatment, and that the people around you know how to support you.

After you leave hospital, you may still need to:

Take medication.

Attend follow-up appointments and assessments with your stroke team.

Attend appointments for rehabilitation services like speech and language therapy, occupational therapy, etc.

Do regular exercises prescribed to you by your stroke team.

Modify your diet to make it easier to chew and swallow.

It is important for you and the people around you to take note of any unexpected changes in your health. This includes new symptoms, side effects of your medication, and changes in how you are coping.

You may also have been given a list of potential side effects to look out for when you started treatment.

If anything changes unexpectedly, speak to your GP or stroke team as soon as possible.

You should also speak to your GP or stroke team if you have any questions, worries, or doubts about your treatment - no matter how minor!

Knowing what is happening, what to expect, and who to speak to can make it much easier to manage the transition from hospital to home. It also means you are safer, and likely to recover better - so if you have a question, ask it!



Strategies for recovery

There is a lot that goes into the recovery process after a stroke, and this booklet cannot tell you how to manage every aspect of your recovery. Speak to your stroke team or our Advice Line practitioners for more individual support with your recovery.

However, there are a few strategies which can be applied to most people who have had a stroke, to make it easier to manage your recovery and the return to home living.

In the next few pages, we will discuss how to:

- **Build a routine.**
- **Set achievable goals.**
- **Keep active.**
- **Get out and about.**
- **Stay in touch.**
- **Feel your feelings.**

Building a routine

One of the best ways to keep up good habits and improve your overall health is to have a routine. This not only makes it easier to manage your rehabilitation and remember things like medication, but also helps with sleep and diet.

Try to do things at around the same time every day, if you can.

Try to arrange your routine around any patterns you notice in how you feel. For instance, if you have more energy in the afternoon than the morning, you might do daily exercises then.

It can help to write down regular tasks and when you plan to do them.

It is important to build time into your day to relax and do things that you enjoy. This is part of your recovery, too!



Setting achievable goals

Knowing what you want out of your recovery can help to motivate you and make it easier to see where you are making progress.

Speak to your stroke team, especially your occupational therapist (if you have one), about setting reasonable goals.

Aim to set several small, shorter-term goals rather than one big goal that might take months or years to achieve.

For example, rather than “I want to get back to how I was before my stroke”, start with “I want to walk around the house”. Once you can do that, set a new goal, like “I want to walk to the end of the street”, and so on.



This sort of goal-setting helps to give structure to your recovery, and to identify what's most important to you.

Keeping active

Keeping yourself moving and physically active is an important part of your recovery. It helps you to build strength and flexibility, improves blood flow, and prevents damage that can be caused by sitting or lying still too long.

If you can walk, go for walks regularly. If you feel unsteady on your feet, you might be more comfortable if a friend, family member, or carer goes with you.

If you cannot walk or stand easily, there are exercises you can do while sitting or lying down. Ask your physiotherapist for advice on exercises you can do safely.



For more information on exercising safely, see our Essential Guide on **Physical Activity**.

Getting out and about

Leaving the house and getting involved with your community is good for your mental wellbeing and can help you to find support.

Leave the house as often as is safe and comfortable. Go to a cafe, take a walk, or sit in the garden.

If you struggle to leave the house under your own power, discuss with your stroke team and carer(s) if there is a way that you can go outside in a wheelchair or similar.

Arranging transport is an important part of adjusting to life after a stroke. You may not be able to go back to driving immediately, and the car you use may need adaptations. In some areas, you might be able to access volunteer transport services to help with travelling to appointments.

For more on transport and driving, see:
Driving with a Medical Condition

Staying in touch

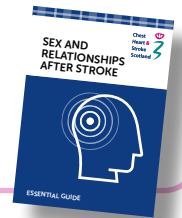
It is important to keep in contact with the people in your life. This can feel intimidating, especially if you have communication difficulties, but the sooner you get back to social activities, the easier it will be.

If you aren't able to go outside, it is helpful to stay connected to people, whether by telephone, internet or visits. The internet makes some social activities more accessible (e.g. support or craft groups). You may have friends or a befriender who can visit regularly

It is also important to stay in touch with your medical team between appointments. Make sure you know who to contact, and how.

For more, see our booklets on:

Communication after a Stroke
Sex and Relationships after a Stroke



Feeling your feelings

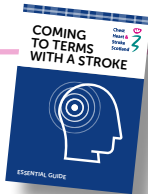
Recovering from a stroke can be an emotional time for you and the people around you. It is important to recognise those feelings and deal with them as they arise.

Talking with other people about how you feel can be helpful. This can be a useful part of stroke support groups. It can also help people around you to know how best to support you.

It may also be helpful to keep a journal of your feelings. This does not have to be written - you could draw, or keep voice notes, or anything you like. The important thing is to give yourself space to explore your feelings and look back on them over time.

Many people find that therapy or counselling are helpful after their stroke.

For more, see our booklets on:
Mental Wellbeing
Coming to Terms with a Stroke



Will I have another stroke?

With proper treatment and by living a healthy lifestyle, you should be able to reduce the chances of another stroke. However, experiencing a stroke does mean you are at a higher risk.

Important steps to prevent another stroke include:

- Taking your medications as prescribed.
- Having regular blood pressure checks and controlling your blood pressure.
- Quitting smoking (if you smoke).
- Dietary and lifestyle changes.

For more ways to reduce your risk of another stroke, see our booklet **Reducing the Risk of Heart Attack and Stroke**.

Advice and support

Finding support in your recovery journey can make all the difference. Ask family, friends, and your stroke team for help where you can.

You can also 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

You can also find a wide range of information, including easy-read and non-English language versions, on our Resources Hub:

www.chss.org.uk/resources-hub

CHSS have stroke support services throughout Scotland, including stroke nurses. Call the Advice Line to find out more about support services in your area.

NHS Inform

The central information hub for NHS Scotland, which has lots of information on stroke as well as many other conditions.

www.nhsinform.scot

Befriending Network

Provides information about befriending and access to befriending networks and projects across the UK.

www.befriending.co.uk

Tel: 0131 261 8799

Care Information Scotland

Provides information and advice if you care for someone or need care yourself.

www.careinfoscotland.scot

Helpline: 0800 011 3200

NHS 24

Out of hours, non-emergency medical support and advice from the NHS.

www.nhs24.scot

Call: 111

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

E38 Published July 2024
Next planned review July 2027

Scottish Charity (no SC018761)