Chest Heart & Stroke Scotland

STROKE: A GUIDE TO RECOVERY AT HOME





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.

STROKE: A GUIDE TO RECOVERY AT HOME

ABOUT THIS BOOKLET	2
WHAT IS A STROKE? What are the signs & symptoms of a stroke?	4 6
RETURNING HOME What can I expect when I go home? Where can I get help and support?	8 8 8
ADJUSTING TO LIFE AFTER A STROKE Fatigue Routines Keeping active and staying in touch Dealing with the emotional aspects of stroke Emotional support for you and your carer Relationships Getting around Back to work Holidays	 13 14 15 17 19 21 21 22 23
REDUCING THE RISK OF HAVING ANOTHER STROKE Am I likely to have another stroke?	24 24
HELP AND SUPPORT FROM CHSS	25
USEFUL RESOURCES	28

ABOUT THIS BOOKLET

STROKE: A GUIDE TO RECOVERY IN HOSPITAL

Who is this booklet for?

This booklet can help you understand what a stroke is and what can happen after a stroke. It explains what to expect in the long term as you return home from hospital.

The booklet provides information on how to manage your recovery at home and offers practical advice what support is available to help 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 straight away, other sections you may want to come back to and read at another time.

This booklet and Stroke: A Guide to Recovery in Hospital are also available for people with aphasia (communication difficulties) - Your Stroke Journey Part 1 - Recovering in Hospital and Your Stroke Journey Part 2 - Recovering at Home



Further information

If you would like more information, Chest Heart & Stroke Scotland have a range of easy-to-read 'essential guides' on a number of different topics discussed in the booklet. This includes guides on Stroke, Transient Ischaemic Attack (TIA), Vision after stroke and Reducing the risk of stroke and heart disease. 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.

WHAT IS A STROKE?

A stroke happens when the blood supply to part of the brain is interrupted. As a result brain cells get less of the oxygen and nutrients that they need. Some brain cells can become damaged and others can die.



There are two types of stroke:

• Ischaemic stroke - this type of stroke occurs when a blood clot blocks one of the arteries which carries blood to the brain. About 85 in every 100 strokes are ischaemic.



• Haemorrhagic stroke - this type of stroke occurs as a result of bleeding within or around the brain from a burst blood vessel. Approximately 15 in every 100 strokes are haemorrhagic.



A **transient ischaemic attack (TIA)** is similar to a stroke, but the symptoms don't last as long. A TIA can last for anything from minutes to hours, but symptoms don't last longer than 24 hours.

See the CHSS booklet Stroke: a guide to recovery in *hospital* for more information on the symptoms and effects of a stroke.

What are the signs & symptoms of a stroke?

Strokes are a medical emergency and urgent treatment is essential because the sooner a person receives treatment for a stroke, the better the outcome is likely to be. If you suspect that you or someone else is having a stroke, **phone 999 immediately and ask for an ambulance.**

The signs and symptoms of stroke are:

- Sudden weakness or numbness, especially on one side of the body. It may be the face, arm, leg or a combination of these
- Sudden blurred vision or loss of sight in one or both eyes
- Sudden confusion, difficulty speaking or understanding
- Sudden dizziness, loss of balance or lack of co-ordination
- Sudden severe headache with no known cause
- Sudden change to facial expression or inability to smile

If you have any of these symptoms, even for just a short amount of time, call 999 for an ambulance.

The FAST test can help you recognise if someone is having a stroke.

"Many people have no idea how to recognise the symptoms of a stroke; this FAST campaign helps raise awareness and encourage everybody to treat stroke as a medical emergency." Christine, stroke survivor

STROKE? Think FAST & save a life CALL 999

ACE – Can they smile? Does one side droop?

RM – Can they lift both arms? Is one weak?

J

SPEECH – Is their speech slurred or muddled?

IME – To call 999.



www.chss.org.uk







RETURNING HOME

What can I expect when I go home?

When you leave hospital you should have a discharge plan. This should cover all the necessary arrangements for your care at home, including links with community services and any special equipment you may need. Going home may feel a bit daunting for you and your carer (if you have one). You may not have fully recovered when you leave hospital and you may need to continue rehabilitation at home. You may also have lots of questions about how you will be able to cope from day to day.

Where can I get help and support?

Your GP practice

Your GP will be in charge of your care once you return home. Your GP can give you general advice about your health and put you in touch with other services and healthcare professionals.

Pharmacy

Your pharmacist is an expert in medicines and can give you advice and information about your medicines.

Stroke nurses and therapists

Many areas now have a stroke nurse or stroke liaison nurse. The stroke nurse can help with the transition from hospital to home. The stroke nurse and therapists will continue to visit you at home to help you adjust by providing advice, information and support; and encouraging and supporting you to self-manage your stroke.

"After having my stroke it was scary going home on my own. I was very worried about the problems I was having and the stroke nurse was very reassuring. She explained everything in a way that I could understand and she understood how I was feeling."

Social services

Community support services to help you manage when you return home can be arranged through your local council's social work department (sometimes called social care or social services).

To find out what support you can get, you will need a community care assessment. This usually happens whilst you are still in hospital. If not, your GP or stroke nurse can refer you to social services for an assessment, or you or a family member can contact them directly. Services available to help you live as independently as possible at home include:

- Help with washing and dressing
- Help with the housework
- Help with shopping
- Help with meals
- Day care services
- Respite care (regular care for a few hours or a short stay in a residential home or hospital) for you and your carers
- Advice on transport, housing and equipment
- Information on benefits

Once you have had your assessment, your care manager/coordinator or social worker will be able to tell you what services are available to you, and whether you will have to pay for them. This will depend on your income and savings; you may need to have an assessment of your financial situation (means testing) to see if you can contribute to the cost. The financial assessment will look at your own income and savings and the local authority will make a decision about how much you are able to contribute towards paying for the services you require.

If you do have to contribute to the cost of any services you will be told how much you have to pay before you accept any services. You can also choose not to have a financial assessment at all, but then you will have to pay the full cost of any service(s) arranged for you.

Aids and adaptations

Aids are things like seating aids for bathing or using the toilet, kitchen equipment and blocks to raise the height of chairs or beds. Adaptations include sloping ramps for wheelchair access, rails and handles to help get up the stairs or steps or sometimes stair lifts.

Equipment

There are many companies that specialise in equipment that can help you cope with day-to-day life. An occupational therapist can advise you on what equipment might be best for you and where you can get it if there is anything you have to buy for yourself.

Wheelchairs are usually funded by the NHS although more complex outdoor and motorised wheelchairs often have to be self-funded. It is important that you have the correct chair and cushion for your particular needs. If you buy one independently, make sure you and / or your carer can use it. Remember it has to fit through the internal doors of your house and you may have to use ramps.

Transport

Contact your local council offices for information about travel concessions and disabled parking for your area such as the blue badge parking scheme.

Benefits and financial help

The benefits system is complex, and changes frequently, so it is a good idea to get advice about what you are entitled to and how to fill in claim forms. There are various benefits and allowances available for people who are ill or disabled, for people who are carers and for people on low incomes. Those on low incomes may also get help with the cost of rent, help with council tax and help with NHS costs such as travel to and from hospital. Your benefits will be handled by your local Department for Work and Pensions.

It is important that you receive all the benefits and allowances you are entitled to. It can be helpful to speak to a social worker or a welfare rights officer at your local social work centre. You can also get information from the Citizens Advice Bureau or local welfare rights organisations including the Money Advice Centre.

Mobile services

There are many additional services that can be provided in your own home, for example dental visits, eye examinations, hairdressers and chiropodists. To find out what is available locally ask your stroke nurse, call the CHSS Advice Line on 0808 801 0899 or phone NHS Inform on 0800 224488.

ADJUSTING TO LIFE AFTER A STROKE

In addition to dealing with the practicalities of living at home and resuming daily life, it is important to find new ways of getting the most out of life after your stroke. In the first few months you may be concentrating on relearning old skills or learning new ones. However, once you know how much recovery is likely, and which areas you can focus on improving, you will be able to rebuild your life and focus on enjoying life again.

Fatigue

Fatigue is one of the most common effects of stroke. It is something that affects most people who have had a stroke, regardless of its severity, and it usually becomes more apparent after returning home from hospital.

Post-stroke fatigue is different to just feeling tired and isn't related to how busy or active you are. Everyone feels tired sometimes and this is often overcome after resting, but fatigue after stroke may feel more like you lack the energy to do anything or constantly feel weary. Sometimes you may feel fatigue comes on very suddenly and all you can do at that point is rest until it passes.

Although the fatigue tends to get slowly and steadily better, it can take months or even years to resolve fully. Most people describe having good days and bad days – days when they feel able to do most things and days when they just have to rest more because they feel more fatigued. As life progresses, good days tend to increase and bad days tend to decrease.

Often the signs of fatigue aren't obvious to other people so it can be difficult to make them aware of how you are feeling. There are, however, ways you can help yourself and get support if you are experiencing fatigue after a stroke. Key to overcoming fatigue is it to pace yourself and realise it is not your fault. Accepting that it may take time to overcome fatigue can also help you cope better over the longer term.

Routines

Daily routines at home can be helpful. They will break up your day and can help you to pace yourself according to your energy levels. When considering a daily routine, consider your own needs as well as anyone else who lives at home with you and/or cares for you. Think about the daily tasks that need to be done and work out which ones you can do on your own, ones that you need help with and ones that you need to re-learn how to do. Think about the time you will need to do these tasks. If you get tired easily try to do the most energy-consuming tasks at the time of the day or week you have the most energy, but be flexible and plan rest time too. It is important to keep as active as possible. Build in short, but frequent, times of the day to practise movements, exercises and skills. Try to continue with hobbies, interests, social or other regular commitments as much as possible. If you can, try to get some fresh air each day too.

Keeping active and staying in touch

Many people who have had a stroke feel self conscious about their weakness, speech difficulties or other impairments. This can lead to a reluctance to see friends and go out, but starting to socialise again is an important step in your stroke recovery.

You may find it difficult going to places you went to before your stroke due to physical problems, or you may be worried that you won't be able to manage when you are out and about. It may seem easier to stay at home but this can lead to isolation and feelings of loneliness and low mood. There is often a solution to overcoming practical difficulties, for example through the support of others or using a wheelchair if it helps to get you out and about. Try to stay in touch with your close friends by encouraging them to visit or, if you can manage it, plan short trips with them. It helps if your friends know what you can and can't do and, as with all parts of your recovery, remember to pace yourself.

New friendships and new social activities might seem daunting at first, but meeting new people can be hugely helpful. Many people find being in the company of other people who have had a stroke to be beneficial for sharing experiences. Chest Heart & Stroke Scotland has many Stroke Groups around the country and there will be other local community activities and groups in your area that you may find interesting and useful too.

Staying positive, keeping active and maintaining relationships is key to your recovery.

"Since joining the session I have been able to stop taking my medicine for depression and I really feel more confident as a result." Chest Heart & Stroke Group member

Dealing with the emotional aspects of stroke

Coming to terms with what has happened to you is an important stage in your recovery and can take time. It is important to remember that everyone's stroke journey and rate of recovery is different. There is no right or wrong about how you are feeling or coping but if you can, try to discuss your feelings with someone you trust.

Many people affected by stroke experience varied emotions and feelings such as:

- Fears and worries it is quite normal for the shock, disbelief and sense of loss to affect you and your family just like a grief reaction. You may feel frightened by lapses in memory or scared another stroke may happen.
- Anger and frustration you may be angry about what has happened to you or frustrated that you can't do what you could do before, particularly if you are having difficulty communicating. Sometimes the effect of a stroke may also make you more irritable with people around you and you may find you are affected by mood swings, which can make it even more difficult for you and your family to cope.
- Depression and anxiety you are likely to feel anxious or upset and this is quite normal. Feeling down is natural for a while after a stroke, but if you are feeling low most of the time you could be depressed and you should tell your GP or nurse how you are feeling.

- Strain on relationships irritability and heightened emotions can put a strain on relationships as you may find you are directing your anger and frustrations at those closest to you and those you least mean to hurt. Try to remember that your family and friends may be struggling to understand how you are feeling. Help is available through your GP or nurse for your family and friends too, to enable them to understand what you are going through and to learn how to cope and support you.
- Loss of confidence feeling a lack of confidence and low self esteem is common after stroke but it is important to focus on achieving as much independence as possible and use any opportunities that arise to boost your confidence. This could be by getting more involved in making decisions about your care, learning new skills or setting yourself realistic goals to achieve.
- Lack of motivation recovery from a stroke is usually gradual and made up of small but significant achievements. If you are feeling tired and low this can affect your motivation to recover more quickly and get out and about again. Setting small but achievable goals can seem frightening at first, but can really help you to stay positive and motivated. It is vital to stay as optimistic as possible. Try to remember that having good and bad days is natural and you need to remember to pace yourself. There are limits to what you can achieve in any one day!

All these feelings are a normal response to a major life event like a stroke. A good way of focusing on your recovery is to get information. Being informed takes away much of the fear and uncertainty around your recovery.

"After a difficult time, I am now not only physically fit, but also able to cope mentally with what lies ahead."

Emotional support for you and your carer

Emotional support is just as important for recovery as physical support and rehabilitation. Family and friends can help in many different ways. Involving them in your rehabilitation and care can help fight feelings of isolation. Their emotional support can also help to increase your motivation to achieve long-term goals.

People affected by stroke often feel like they're on their own but it doesn't have to be this way. There are many sources of support that can help make a difference as you adjust to life after stroke. These can range from local support groups and counselling services through to helplines such as the CHSS Advice Line Nurses who can provide confidential information, advice and support on all aspects of living with a stroke both for yourself and your carer. It is important to be aware of the emotional wellbeing of your carer. Caring for someone who has had a stroke can be physically and emotionally demanding. The person caring for you may need help in terms of having someone to talk to or getting advice on benefits or accessing other support services.

"The support of the stroke nurse gave us the most important thing of all – HOPE – when we most needed it, and time has proved her right. We now see a future living with stroke."

Carer

Relationships

A stroke doesn't just affect you but everyone around you too. Relationships can be complex and often our relationships can be affected by the way we feel about ourselves. Family and friends may also be struggling to understand how you are feeling so be honest with them. Talking to them about your feelings and trying to understand how they are feeling can really help.

Adjusting to life after a stroke is likely to be as lifechanging for your partner as it is for you and so relationships can be put under a lot of strain. Emotional changes, physical problems and relationship difficulties may also have an effect on your sex life.

Getting around

After a stroke your ability to drive safely can be affected in various ways including physical or visual impairment, or you may have difficulty concentrating for long periods of time. After a stroke, you are not allowed to drive for the first month. After this time you should see your GP who can give you advice on whether you can start driving again. You may need to be referred for a driving assessment.

It is important to tell your car insurance company that you have had a stroke to ensure that your policy remains valid. You do not usually need to let the DVLA know if you have had a single stroke. However, there are certain circumstances when you do need to inform the DVLA – your GP will be able to advise you. If you are not able to drive, some local councils provide community transport schemes for people who have disabilities and are unable to use public transport.

Back to work

The effects of a stroke can create particular challenges if you were previously working. There can be a huge impact on your life in terms of earning a living and your role in your family and in society. Some people can be unrealistic about returning to work and so look to take on too much too soon. Tiredness, cognitive issues such as memory loss, and difficulty concentrating can mean returning to your old job might not be possible or may not be suitable for you anymore. It is very important to speak honestly with your employer so that you do not put yourself under too much pressure to perform and so that they can consider making reasonable adjustments to your role or to your workplace if possible. Working part-time or with a reduced workload may be possible. Don't be too hard on yourself if things don't work out the way you want them to or exactly as they were before your stroke. Many people do make a success of returning to **work.** Some see it as an opportunity to try something else, work from home or take up a new challenge. A Disability Employment Advisor at your local job centre can advise on careers or retraining if this is the best option for you.

Holidays

Holidays are an important part of life, but it can be difficult to know where to start to find something suitable or begin to think about travel logistics. Some organisations will make all your arrangements including travel and assistance. Whatever your needs, there will be some help available.

REDUCING THE RISK OF HAVING ANOTHER STROKE

Am I likely to have another stroke?

Having one stroke increases your risk of having another one. However, there are some things that you can do to help reduce your risk of this happening. These include:

- Taking your medicines as prescribed
- Managing your blood pressure
- Managing your cholesterol
- Controlling diabetes (if appropriate)
- Addressing your lifestyle to reduce any risk factors you have.

Changes to your lifestyle might include:

- Stopping smoking
- Eating a healthy and varied diet
- Maintaining a healthy weight
- Keeping physically active
- Moderating your alcohol intake
- Avoiding recreational drugs

HELP AND SUPPORT FROM CHSS

Advice Line

Call our award-winning confidential Advice Line on 0808 801 0899. Staffed by nurses, the Advice Line is open Monday to Friday 9.30am – 4.00pm and provides confidential, independent advice on all aspects of stroke illness. Whether you need someone to talk to or you are looking for details of local services, the Advice Line nurses will help with any information you or your family needs if you have been affected by stroke. 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.

Stroke Services

We provide support for people who have difficulty with communication and physical and everyday tasks after a stroke. The type of support available may differ depending on where you live in Scotland. The aim is to help you to increase your confidence and to support you to do the things you want to do when you are back home, so that you can live more independently. Support is provided through one-to-one support or in a small group.

In some areas of Scotland, CHSS provides support from a stroke nurse or occupational therapist as you leave hospital after a stroke. The stroke nurse or therapist will work with you and support you and your family for up to a year after you leave hospital. Your hospital stroke care team will need to refer you for this service if it is available in your area.

Support Groups

Hearing how other people are coping after stroke can be a lifeline for some people. CHSS has a number of support groups across Scotland for people who have been affected by stroke. The groups offer a wide range of support including exercise, social activities and an opportunity to talk to others who understand what you are going through. These groups are run by people living with stroke or other long-term conditions and are supported by CHSS.

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 benefits available. 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

Action on Depression

Tel: 0131 226 1803 Email: info@actionondepression.org Website: www.actionondepression.org Action on Depression is the only national Scottish organisation working with and for people affected by depression.

Age Scotland

www.ageuk.org.uk/scotland Tel: 0800 12 44 222 Provides a wide range of information and advice for older people.

Befriending Networks

www.befriending.co.uk Tel: 0131 261 8799 Email: info@befriending.co.uk Provides information about befriending and access to befriending networks and projects across the UK.

Bladder & Bowel Community

www.bladderandbowel.org Tel: 01926 357220 Email: help@bladderandbowel.org The Bladder and Bowel Community provides information and support for people with bladder and bowel disorders.

British Red Cross

www.redcross.org.uk Tel: 0344 871 1111 Email: contactus@redcross.org.uk Has local branches which can lend or hire equipment for people with disabilities. They can also help with transport and first aid training.

Care Information Scotland

Helpline number: 0800 011 3200 Website: www.careinfoscotland.scot Provides information and advice if you care for someone, need care yourself or are planning for your future care needs.

Carers Scotland

www.carersuk.org/scotland Tel: 0141 445 3070 Advice Line: 0808 808 7777 Email: info@carerscotland.org *Carers Scotland provides information on all matters relating to caring.*

Carers Trust

www.carers.org Tel: 0300 772 7701 Email: scotland@carers.org Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring for a family member or friend.

Citizens Advice Scotland (CAS)

www.cas.org.uk Tel: 0808 800 9060 Online advice and contact details of your local citizens advice bureau. Offices in Edinburgh, Glasgow and Inverness.

Diabetes UK Scotland

www.diabetes.org.uk/scotland Tel: 0141 245 6380 Helpline: 0141 212 8710 Email: scotland@diabetes.org.uk Diabetes UK Scotland works to raise awareness, improve care and provide help, support and information for people with diabetes and their families across Scotland.

Different Strokes

www.differentstrokes.co.uk Information line: 0345 130 7172 Email: info@differentstrokes.co.uk Different Strokes helps young stroke survivors reclaim their lives through active peer support and independent recovery.

Directgov

www.direct.org.uk

UK government website which provides a single point of access to information and practical advice about public services. It has information about financial benefits as well as information for disabled people and carers. (NB Some policies / services may be different in Scotland.)

Disabled Living Foundation

www.dlf.co.uk Helpline: 0300 999 0004 Email: info@dlf.org.uk Provides impartial advice, information and training on independent living.

Epilepsy Scotland

www.epilepsyscotland.org.uk Tel: 0141 427 4911 Helpline: 0808 800 2200 Email: helpline@epilepsyscotland.org.uk Works with people living with epilepsy to ensure their voice is heard.

Headway

Tel: 0115 924 0800 Email: enquiries@headway.org.uk Helpline: 0808 800 2244 or helpline@headway.org.uk A UK-wide charity that works to improve life after brain injury.

Lead Scotland

www.lead.org.uk Tel: 0131 228 9441 Fax: 0131 229 8082 Email: enquiries@headway.org.uk Helpline: 0808 800 2244 or helpline@headway.org.uk *A UK-wide charity that works to improve life after brain injury.*

NHS 24

www.nhs24.scot Tel: || | The phone service is designed to help you get the right help from the right people at the right time. The website provides comprehensive up-to-date health information and self-care advice for people in Scotland.

RNIB Scotland

www.rnib.org.uk/scotland Tel: 0131 652 3140 Email: rnibscotland@rnib.org.uk Provides a wide range of specialised information and services for people with sight loss.

Relationships Scotland

www.relationships-scotland.org.uk Tel: 0345 119 2020 Email: enquiries@relationships-scotland.org.uk Relationships Scotland offers confidential relationship counselling and sexual therapy for couples and individuals.

Shaw Trust

www.shaw-trust.org.uk Tel: 01225 716300 Provides information and employment services for disabled and disadvantaged people across the UK.

The Tavistock Trust for Aphasia

www.aphasiatavistocktrust.org Tel: 01525 290 002 Email: TTA@tavistocktrustaphasia.org Works to improve the quality of life for those with aphasia, their families and carers.

Visibility Scotland

www.visibility.org.uk Tel: 0141 332 4632 Email: info@visibility.org.uk Provides a range of services and activities for people who are visually impaired.

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:



www.chss.org.uk



healthinformation@chss.org.uk



0131 225 6963



Rosebery House, 9 Haymarket Terrace, Edinburgh EH12 5EZ

Chest Heart & Stroke Scotland

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

Chest Heart & Stroke Scotland Rosebery House, 9 Haymarket Terrace, Edinburgh EH12 5EZ Tel: 0131 225 6963 | Open Mon – Fri

www.chss.org.uk

Published 1 July 2018 (revised September 2020)

Registered with and regulated by the Office of the Scottish Charity Regulator (no SC018761), Chest Heart & Stroke Scotland is a wholly Scottish charity. It also operates as CHSS and is registered in Scotland as a company limited by guarantee, no SC129114

