



**Information & support for carers of
people living with stroke**

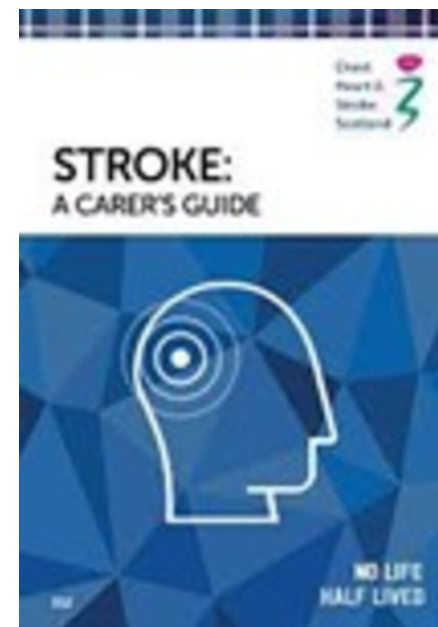
Introduction



Introduction

This resource provides practical advice to support you in your role as a carer. **Stroke: A carer's guide** ([PDF](#)) is a recommend read when you begin caring for someone who has a had a stroke.

Am i a carer? You may not think of yourself as a 'carer' but if you are a partner, relative or friend of someone who has had a stroke and you are involved in their care this applies to you. In Scotland, we also use the term 'unpaid carer' for anyone providing care for a family member or friend. It doesn't matter if you call yourself a 'carer' or 'unpaid carer', or none of these terms! The important thing to remember is that there is support out there if you are caring for someone close to you.



As a carer (1)

As a Carer:

- There are no set hours.
- The person you care for may be in their own home, or your house.
- The person you care for may or may not have formal support from social care or others.
- You may or may not receive Carers Allowance.
- It is important that you feel supported and able to cope.

Image and text 'Are you a carer? You don't need to be living in the same household as the person you are providing care to' & 'Are you a carer? You don't need to be providing regular and substantial care in order to be recognised as a carer' taken with kind permission from Coalition of Carers in Scotland: From Recognition to Rights (carersnet.org)



As a carer (2)

Carers, whatever their age or circumstances, may need information, practical help, and support. With your encouragement and support, combined with the right professional guidance, you can make a big difference to the person you care for; however, it is important you take care of your own health and wellbeing to allow you to do this.

Image and text 'Are you a carer? The person you care for doesn't need to be receiving a social care package in order for you to be recognised as their carer' taken with kind permission from Coalition of Carers in Scotland: From Recognition to Rights (carersnet.org)



Your rights as a carer



Your rights as a carer (1)

The [Carers \(Scotland\) Act 2016](#) (updated 2021), ensures that carers have a legal entitlement to:

- Adult carers have a right to an '**adult carer support plan.**' The adult carer support plan will contain a variety of information about the adult carers circumstances and caring role.
- Young carers have a right to a '**young carer statement.**' The young carer statement will contain a variety of information about the young persons own circumstances and caring role.
- Carers have a right to support to meet any '**eligible needs.**' The adult carer support plan or young carer statement will identify the needs of the carer.



Your rights as a carer (2)

- Carers have a right to be **involved in services**. Local authorities and health boards must consult carers on services for them and the person they are caring for.
- Carers have a right to be **involved in the hospital discharge process** of the person they are or are going to be caring for. Each health board must ensure that, before a cared-for person is discharged from hospital, it involves the carer in the discharge of the cared-for person.
- Carers have the right to **access to local information and advice** service(s).

Image taken with kind permission from Coalition of Carers in Scotland: From Recognition to Rights (carersnet.org)





Emotional effects of being a carer

Emotional effects of being a carer

- There is a lot to take in over the first few weeks after a stroke.
- You may feel overwhelmed by the volume of information and practical arrangements being made for the person you are caring for.
- Even if you can't take it all in straightaway, or don't think you'll need it, keep hold of all the information and useful contacts you are offered. Your needs and those of the person you care for are going to change over time.
- It may be difficult to know what questions to ask or who and when to ask them.
- Remember you are not alone & it is ok to ask for help and support.
- More information and advice is available from Carers UK: [Being Heard: a self advocacy guide 2021](#).



Advice from other carers

Advice from other carers

Experienced carers say the most important things are to:

- Look after your own health. A priority is to make sure you are ok so you can be there for the person you are caring for.
- If you are feeling overwhelmed, you can talk to your GP. It's important that they know you are caring for someone who is recovering from a stroke.
- Ask for information about what services and support are available.
- Sort out practical help with the daily routine, don't be a carer on your own.
- Plan to take regular breaks, both at home and getting time away.
- If you are employed or in full time study, it may help to let your employer, or your tutor know what is happening at home so they can support you.
- Carers Centres can be very good sources of local information and good places to meet other carers who know what you are experiencing, first hand.

These practical steps won't necessarily make difficult or painful feelings disappear, but they can make it easier to talk about how you are feeling and get you the help you need to cope with the day-to-day tasks of caring. They can also help to give you some valuable time to yourself to recharge your batteries



**Social care help for the person
you are caring for**

Social Care help for the person you are caring for

Each local council has a social work department (sometimes called social care or social services) which has a major responsibility for organising/coordinating community care services:

- If someone needs support services in order to manage at home after a stroke, these are usually arranged through this department.
- The services available vary from area to area, but include things like help with personal care, special equipment or adaptations to the home, day care, home care assistants, meal service and respite care.
- A care package to help with personal care tasks and meal preparation may be arranged before discharge but can also be arranged once the person gets home.



Social care assessments and reviews

Arranging a social care assessment

During their stay in hospital your relative will have been assessed by therapist/s. This information will then be shared with social work services if ongoing care is required.

Health & social care staff who put together the 'Discharge from Hospital Plan' for the person you care for have a legal duty to involve both you and them you in the design and review of this plan.

If ongoing support is required, the person you care for will be asked to take part in an assessment by the worker from your local social work team. You can be involved in these conversations; with the consent of the person you care for.

These conversations will work out what services and support are best for the person you care to help them with their rehabilitation, recovery, adapting to change and what costs, if any, will be charged by the local authority.

You can contact social work at any time. Contact the general social work department for your area and ask to speak to the duty social worker.

You can contact social services directly to ask for an assessment if there is a change in circumstances, either your own or the person you are caring for.

Arranging an Adult Carers Support Plan

All carers are entitled to an Adult Carers Support Plan. This plan will help you get the support and advice you need if you experience any changes to your life as your caring role develops. This can be when the person who has had the stroke is in hospital, when they come home, as their care package is put in place and for as long as you need help and advice after this.

This means that you can have the time to think about what you need to support you as a carer and how this help can best be provided to you. The Adult Carers Support Plan is for anyone who has a caring role even if you don't live with the person you are caring for.

The **Adult Carers Support Plan (ACSP)** is to work out with you:

- How much care you are providing and whether you can continue to do this. You have a choice as to how much care you are able to provide.
- The **ACSP** helps your local council decide whether you are eligible for support from or arranged by them. This is called statutory “**Self-Directed Support**.”

Even if you don't meet the **threshold** for **statutory** support, (which can differ in each local authority area) you are still entitled to be supported by your local carers centre.



Arranging a financial review

Arranging a financial review

Caring for someone who has had a stroke is likely to involve extra expenses. It may also mean a drop in income if you or the person you care for has to give up work. You may both be entitled to financial benefits, which will help you to meet some of these costs:

- There are different benefits and allowances for people who are ill or disabled & for people who are carers.
- Ensuring you have the correct package of benefits and entitlements can be very complex as no two households' circumstances are the same. It is important that you get expert advice from your local [Citizens Advice Scotland](#)
- **NB:** As a carer you should not have to give up your work. Please seek advice before making any life changing decisions.
- The gov.uk website has lots of useful information about financial support and benefits including an online benefits advisor calculator: <https://www.gov.uk/browse/benefits>
- More information on financial support is available in a separate Tailored Talk.

Other sources of information are: [Social Security Scotland](#) & [Benefits and grants](#)

Carers Centres



Carers Centres

Carers centres are unique to their local area, however they all provide the following support to carers:

- Information and Advice
- Communications including social media
- Available to both Adults and Young carers
- Emotional Support
- Counselling
- Peer Support Group
- Respite Activities
- Advocacy
- Learning and Skills
- Short Breaks (support to access & funding)
- Whole Family Approach
- Emergency and Anticipatory Care Planning
- Supporting carers to have their voices heard

Find the Carers centre closest to you here: [Care Information Scotland](#)

Things to remember



Things to remember (1)

Keep communicating:

- You can achieve a lot by being honest and open with your partner (or the person you care for) and with yourself. Try not to be overprotective. You are not in charge of their illness. You can't make him / her healthy but, if you're overprotective, you can make him / her feel like an invalid.

Try to be positive:

- There will be bad days. Don't be discouraged. Remind yourself that negative thoughts are just that: thoughts, not facts. Be determined not to let the illness take over both your lives. Your partner is not a victim; neither are you. Make a list of activities both of you could enjoy. Plan to do at least one every day.

Things to remember (2)

Encourage independence:

- Make bargains with your partner, e.g. 'If you do your exercises, I'll make the tea'. If your partner is afraid to do something that you know he or she can do, don't do it. Ask yourself 'Am I doing this for my partner or am I doing it for myself, so I can feel useful?'

Make time for yourself:

Find things to do at home that will take your mind off worrying about your partner. Take a break, away from the house. Ask family or friends to stay if you are anxious about leaving your partner alone. Above all try to remember that you are not alone. It is ok to ask for help and support.



**CHSS information and support for
you**

CHSS information & support for you

CHSS are here to support you as well as the person you care for:

- Talk, in confidence, to one of our [Advice Line Team](#) offering free, confidential support, information and health advice for people living with stroke, service users, carers, and health & social care professionals across Scotland. Call (free) Tel: 0808 801 0899 Email: advice@chss.org.uk or Text: NURSE to 66777
- Visit [Stroke4Carers](#), an interactive website for stroke carers, family and friends of anyone affected by stroke.
- Download or order from our health information [resources hub](#), including [Stroke: A carer's guide \(PDF\)](#)
- Find out what [financial support](#) is available for you.



Other sources of support

Other sources of support

Further advice & support for carers can be accessed through:

- Befriending Networks
- Care Information Scotland
- Carers Trust
- Carers Scotland
- CHSS
- Coalition of carers in Scotland- from recognition to rights
- MECOPP Carers Centre
- Patient Advice & Support Service
- Shared Care Scotland & Shared Care Scotland-Residentiality

Information used to create this resource

Information used to create this resource has been taken with kind permission from:

- Stroke 4 carers: <http://www.stroke4carers.org/>
- CHSS Support for carers: <https://www.chss.org.uk/support-carers/>
- CHSS Booklet-[Stroke a carers guide](#).
- All CHSS Heath information publications: [CHSS Resources Hub](#)
- Other websites are also referred to/signposted in this resource including:
carers.org, carersuk.org/scotland, befriending.co.uk and sharedcarescotland.org.uk

If you have any comments/changes/suggestions on CHSS Tailored Talks please contact:

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The following organisations contributed to this presentation

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