


Life after stroke

Stroke
association



Life after stroke

**Help and support for you
and your family after stroke**

We're for life after stroke

Need to talk?

Call our confidential Stroke Helpline on **0303 3033 100**.

You may also find our other leaflets helpful.

- We are the Stroke Association
- What is a stroke?
- How to prevent a stroke
- When a stroke happens
- The road to recovery

We also have lots more useful information. To order leaflets and factsheets, or to find out more about stroke, please call **0303 3033 100**, email **info@stroke.org.uk** or visit us at **stroke.org.uk**.

We are a charity. We rely on your support to change lives.

Produced by the Stroke Association's Information Service. To see which references we have used, visit **stroke.org.uk**.

Please call us on **0115 871 3949** or email **quality@stroke.org.uk** if you are unhappy with us in any way. We will happily discuss any issues and help sort them out.

The Stroke Association is registered as a charity in England and Wales (No 211015) and in Scotland (SC037789). Also registered in Northern Ireland (XT33805), Isle of Man (No 945) and Jersey (NPO 369).

Introduction

Stroke changes lives. It can have a huge effect on you and your family. You will probably want to know as much as you can about what practical, emotional and financial support is available.

This leaflet tells you about the people and services that can help you cope after a stroke. Services vary from area to area, so talk to as many people as you can – like a social worker, your GP and our Stroke Helpline – to find out what is available near you.

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"I'd say to anyone in my situation that they should not panic and take the support offered. Don't think your life is over if you have a stroke."

Claire, stroke survivor



What happens after a stroke?

"I stayed positive and found the determination to carry on doing some of the things I had done before my stroke."

Ivor, stroke survivor

After a stroke, you will probably need to spend some time in hospital. It might be a few weeks or months before you will be ready to leave hospital.

The stroke team involved in your care will include specialist doctors, nurses, social workers and therapists. They will work out what care you need, and will help you move from hospital to home when the time is right.

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 ongoing rehabilitation at home. You may also have lots of questions about how you will be able to cope from day to day.



Who can help?

A number of different people can support you after a stroke. Your GP is responsible for your medical care when you are at home. They can give you general health advice and put you in touch with other professionals, depending on what help you need. You may also be able to contact some services yourself.

It is not always easy to get all the support you need. Persevere, and talk to as many people as you can. You can use this leaflet for reference.

Other people who can help

- **Stroke consultants** are medical doctors. They will co-ordinate your treatment while you are in hospital and you may have follow-up appointments with them after you return home.
- **Physiotherapists** can help you recover your movement, strength and balance.
- **Speech and language therapists** help you improve your communication and swallowing.

Have you seen our free magazine **Stroke News**? We produce this magazine every four months. To sign up to receive copies in the post call 01604 687 721 or visit stroke.org.uk.



Who can help?

"Intensive speech therapy helped me after my stroke. I was back at work after about six months. I was a bit impatient – I wanted to go back a month earlier."

David, stroke survivor

- **Occupational therapists** help you find ways to continue your everyday activities. They can arrange equipment and home adaptations.
- **Community or district nurses** can visit you at home to help you take medication and arrange for social services to provide equipment such as a wheelchair, commode or hoist.
- **Continence nurses** can help if you have problems with your bladder or bowels.
- **Community psychiatric nurses, clinical psychologists and counsellors** help with the emotional effects of a stroke, including depression, anxiety and personality changes.
- **Pharmacists** can give you advice about medication.
- **Dietitians** can give you advice on eating healthily, especially if you have difficulty swallowing, are underweight or overweight, or have diabetes.
- **Ophthalmologists and orthoptists** can help with visual problems caused by your stroke.



Social services

Support services to help you manage at home are usually arranged through your local council's social services department. You may have already seen a social worker in hospital. If not, your GP can refer you to social services, or you or a family member can contact them directly.

Getting assessed

If you have had a stroke you are entitled to a community care assessment, and your carer (if you have one) is entitled to a carer's assessment. These assessments should happen before you leave hospital, but sometimes they happen afterwards.

Be honest at your assessment and give as much information as you can about your situation. Mention your health, how you spend your time, what practical support you need and how you are feeling.

What help can I expect?

Once the social worker has carried out your assessment and knows what your needs are, they will tell you about what services are available, and whether you will have to pay for them. This will depend on your income and savings.

A social worker or occupational therapist can assess you and arrange for:

- **mobility aids**
- **adaptations to your home, such as handrails, and**
- **equipment to make your life easier, such as easy-to-grip cutlery.**



Social services

Services vary from area to area, but might include:

- advice and help applying for benefits and grants
- providing equipment and home adaptations recommended by a community nurse, physiotherapist or occupational therapist
- a place at a day centre – which may include transport to and from home, a hot meal and social activities
- visits from care assistants to help with practical tasks such as washing and dressing, and
- home services, such as delivered meals, a laundry service or respite care (regular care for a few hours or a short stay in a residential home or hospital to give you and your carer a break).

What if I can't go home?

If you have had a severe stroke, living at home may not be the best option for you. A social worker can help you think about the amount of care you need, and consider other options, such as:

- sheltered housing – independent accommodation that has a warden on hand for emergencies
- a care home, which provides basic personal care, or
- a care home with nursing, which has fully qualified nursing staff to provide 24-hour nursing care.



Help for carers

Caring for someone who has had a stroke can be physically and emotionally demanding. The person you care for may need help with everyday tasks like washing and dressing. They might find it difficult to understand certain things or tell you what they would like or how they are feeling. They may be depressed or seem like a different person. After the first burst of recovery after a stroke, improvements may be gradual and this can be frustrating for everyone.

It's important that you get all the help you can. This may include having someone to talk to, getting advice on benefits, or arranging respite care to give you a proper break. Your council may be able to provide direct payments to you or the person you care for. This gives you the flexibility to arrange the support you need yourself. For more information, see our factsheet 'Stroke: A carer's guide'.

Tips for carers

- Find out if we can provide services or if there is a carers' centre near you.
- Look after your own health – get enough sleep and try to eat healthily.
- Keep up with your own hobbies and social activities.
- Ask for help – find out what resources are available. Talk to your GP or social worker, especially if your situation changes.

"Being a carer can be incredibly hard. I felt like my husband's personality had completely changed and I felt very isolated. Talking to people in a similar situation helps enormously."

Christine, carer



Support we can offer you

"The Communication Support Service I attend is good fun and you feel as if you are walking in to see old friends and they all support one another."

Marjorie, stroke survivor

Stroke Helpline

If you or your family need information about stroke, details of services in your area or just someone to talk to, please contact us.

- Call us on **0303 3033 100**.
- Email us at **info@stroke.org.uk**.
- Write to us at Stroke Information Service, Life After Stroke Centre, Church Lane, Bromsgrove, Worcestershire, B61 8RA.
- Visit our website at **stroke.org.uk**.

The following services are available in parts of England, Northern Ireland and Wales. They are only available in areas where we have funding from local health or social services.

Information, Advice and Support Services

Our staff can visit you at home or in hospital and talk to you and your family, helping you to cope with the physical and emotional effects of your stroke. They can give you practical advice and emotional support, and help you get support from other services.

Communication Support Services

About a third of people who have had a stroke have difficulty speaking, reading or writing (called aphasia). This service sets up regular group sessions or home visits, helping you to rebuild your communication skills.



Our services

In some areas we can offer other types of support.

Back to Life Services work with you to help you explore opportunities, set goals and get back into work, education, socialising, hobbies or whatever is important to you.

Long-Term Support and Peer Support Services help put you in touch with other people who have had a stroke.

Stroke Prevention Services work with you to reduce your risk of having a stroke.

Life After Stroke Grants

We provide one-off grants up to £200. Grants are means-tested, so we consider your household's income and your savings. To find out more, talk to your local information, advice and support co-ordinator or ask your social worker, therapist or other healthcare professional to contact us.

How to contact others who have had a stroke

Stroke clubs provide a meeting place for people who have had a stroke. Group meetings can give you a chance to share experiences with others who understand what you are going through, and to enjoy social activities. For more information on the clubs in your area, contact us.

You may also like to join TalkStroke, our online discussion group, at stroke.org.uk/talkstroke.



Applying for benefits can be complicated, but there is help available. Speak to your social worker or local citizens advice bureau (CAB) for advice about what you are entitled to and help with filling in forms.



Help from your employer

Depending on your contract with your employer, you may be entitled to a period of paid time off. After this ends, you may be able to claim Statutory Sick Pay (SSP). This depends on how long you've been employed, your age and how much you earn. You can receive SSP for up to 28 weeks. After this, if you are still unable to work, you can apply for Employment and Support Allowance.

Help from the Government

- If you are not entitled to Statutory Sick Pay, or this has ended, you may be entitled to Employment and Support Allowance.
- Disability Living Allowance (DLA) is for people under 65 to help with personal care and mobility. You can claim this alongside other benefits and income, as it is not based on your financial situation. Payments usually start three months after your stroke.

Please note, there will be changes to benefits in 2013. From April 2013, Personal Independence Payment will start to replace Disability Living Allowance. See the useful contacts on the next page for more information.

- Attendance Allowance is for people aged 65 and over who need help with personal care. Payment starts six months after a stroke.
- If you care for a disabled person for more than 35 hours a week, you may be entitled to Carer's Allowance, depending on the benefits they claim and your other income.

If you are renting your home, you can apply to your local council to claim Housing Benefit or Council Tax Benefit (Rate Relief in Northern Ireland). The council may reduce your council tax if you are living alone or need an adapted home.

If you have a mortgage, speak to your mortgage provider. Also check your insurance policy if you have one. Citizens Advice can give you more information.

If your household is on a low income, you may be entitled to other benefits, such as Income Support, Working Tax Credit or Pension Credit. These benefits are paid to your whole household. So if you are living with a partner, both of your incomes will be taken into account. For more information see our resource sheet 'Benefits and financial assistance'.

Useful contacts

Benefits Enquiry Line – phone 0800 88 22 00 (or 0800 22 06 74 if you live in Northern Ireland)

Citizens Advice – visit www.citizensadvice.org.uk

Age UK – visit www.ageuk.org.uk

www.gov.uk (www.nidirect.gov.uk in Northern Ireland) – a Government website with information on benefits and claim forms you can download.



Life after stroke

"I walk my dog, go on holidays and have written a book."

Eric, stroke survivor

Although having a stroke may bring changes, with the right help, at the right time, there is life after stroke.

Going back to work

Returning to work will depend on how much recovery you make and the sort of job you do. Your GP or a stroke specialist can help you decide if you are well enough to go back to work. Discuss all your options with your employer. Many people who have had a stroke go back to work full-time or part-time, or might move to a different job with the same employer.

For more information, see our factsheet 'Stroke in younger adults'.

Leisure activities and holidays

You can continue to enjoy hobbies after your stroke, or it may be the time to take up a new activity, perhaps something you have always wanted to try. Contact us for copies of 'Leisure activities after stroke' and 'Holidays after stroke'. These have lots of ideas for activities, and list organisations that provide suitable accommodation and advice on travelling.



Driving

After a stroke, you are not allowed to drive for the first month. After this time you need to see your GP, who can give you advice on whether you can start driving again. Whether you can go back to driving depends on how your stroke has affected you and what sort of vehicle you drive.

If you can drive again after a month, you do not need to tell the Driver and Vehicle Licensing Agency (DVLA) – or The Driver and Vehicle Agency (DVA) if you live in Northern Ireland – but you should tell your insurance company.

If you cannot drive again after one month, you need to contact the DVLA (or DVA), who will send you a medical questionnaire to fill in. You may be offered an assessment at a mobility centre.

Most local areas have community transport schemes if you cannot travel easily. For more information speak to your social worker or contact your local council. You may also be able to apply to your local council for a free bus pass, or apply for a Disabled Person's Railcard for reduced train fares.

To find out more, see our factsheet 'Driving after stroke'.

"I couldn't speak or move after my stroke, but with the help of professionals and my family, the words came back and I'm now working, going on holidays and driving."

Jennifer, stroke survivor



We are the Stroke Association

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research into finding new treatments and ways of preventing stroke.

We're here for you. If you'd like to know more please get in touch.

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

Email: info@stroke.org.uk

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