

Stroke: a carer's guide

When someone close to you has had a stroke, they may need help and support after they return home from hospital. This guide outlines some ways you can support a stroke survivor, and explains what help and support is available for carers.

What is a carer?

A carer is someone who provides unpaid support to family or friends who could not manage without this support. Around one in eight adults in the UK are carers. Often people do not choose to become carers, it just happens. Many people feel that they are doing what anyone else would do in the same situation.

Being a carer can be a kind, admirable and selfless act. At times though, it can be challenging, and carers sometimes feel overwhelmed, exhausted and isolated. Taking on caring responsibilities can also affect your finances. If you are about to start caring for someone after a stroke it is vital that you have the right information and support to help you both.

Coping in the early days

Stroke is a sudden and serious condition and can come as a shock. Suddenly seeing a loved one unwell can be very upsetting. You might not understand what has happened or may find it difficult to know how to support them. It is natural to feel overwhelmed, but as you come to terms with what has happened, you might

want to know how you can help. Here are some ideas.

- Start by talking to the medical team. Ask them to explain what has happened and clarify anything you do not understand.
- While your loved one is in hospital, it can help to keep a note of day-by-day changes. The medical team will find this helpful, as you may be the first to be aware of any changes or improvements. For the person who is recovering, this may become a precious record of their progress since their stroke.
- Ask the medical team whether there are any small ways in which you can assist with your loved one's care. As time goes on, ask the rehabilitation team to show you ways to provide support between therapy sessions. This could mean helping your loved one re-learn skills, or practising therapy exercises together.
- Focus on one day at a time. Recovering from a stroke is a gradual process. Encourage and motivate your loved one as much as possible.

- Keep hold of useful information and contacts. Your needs can change over time, and you may find it is helpful in future.
- Remember to look after yourself. Take breaks, get some exercise and plenty of sleep, and plan regular healthy meals.

The impact of stroke

Stroke can have many different effects on someone, including problems with mobility, swallowing and continence. It can affect their vision, and cause communication problems, fatigue and problems with memory and concentration. It can also have emotional effects, like depression and anxiety. It can also cause personality changes. These changes can have a big impact on everyone in a family as well as the stroke survivor.

You may feel a deep sense of loss as the person you know and love may not seem to be the same. And sometimes, these changes can affect your feelings towards them.

Keep reminding yourself, and others, that any changes are the result of the stroke and that they have no control over them.

Working together with family or friends and supporting one another will help you all to come to terms with what has happened.

Family members who live far away also have a role to play in keeping up morale. You may find it helpful to nominate a contact person, who can keep the rest of the family informed. This will take some pressure off you and give you more time to rest and recuperate.

Recovery

The amount of recovery someone will make and the amount of time it takes varies. The biggest improvements usually takes place in the early weeks or months, but recovery can continue for years.

Some people make an almost full recovery. Most people recover enough to be able to do many of the things they did before, perhaps with some support. Some people will have disabilities and other problems. Depending on the effects of their stroke, they may need help to live independently, or they may need to live in residential care.

If your loved one is likely to need a lot of support after leaving hospital, you may decide to become their main carer, responsible for their day-to-day care.

Caring for someone can take up a lot of energy, so it should not be undertaken lightly. It may be helpful to talk to someone before you make a decision about becoming a carer. If you were already caring for someone before they have a stroke, the effects of the stroke may have changed the amount or type of care they need. For more information can call our Stroke Helpline, or contact one of the carers' charities (see *Other sources of help and information*).

Leaving hospital

Some people leaving hospital after a stroke only need a small amount of care, but others have more complex needs. The medical team and social services should work together with you, and the person you are caring for, to create a care plan based on their needs.

Part of this process should include a care needs assessment for your loved one to determine what support they need, and a carer's assessment to identify your needs as a carer.

Carer's assessment

If you are, or are thinking about becoming a carer, you have a right to have an assessment of your needs. This is called a carer's assessment. You are entitled to an assessment and to receive help even if the person you care for refuses help.

A social worker, or another professional nominated by the local authority, will carry out your assessment. They will look at your role as a carer and the effect it has on you. The assessment will establish how much caring you do (or will do) and how that affects other areas of your life such as work, training or leisure activities. You can ask for the assessment before you start caring, or at any other stage if you have already started being a carer.

Before your assessment, think carefully about what kind of support you might need. This can be difficult if the person you are caring for has not returned home yet, but staff at the hospital may be able to give you information about the tasks your loved one will need help with.

What help will we receive at home?

Healthcare

Once the person you are caring for is at home, their GP becomes responsible for their medical care. The medical team should write to the person's GP, giving information about their treatment and future care needs, including medication. You may wish to contact the GP to ensure that they know the person you are caring for is coming home.

Specialist stroke nurses or district nurses can provide nursing support for people living at home. The GP can make a referral to see one. They may offer practical help with tasks such as moving, washing, feeding and dressing, and show you how to do them safely. They will also have skills in more specialist areas such as feeding for people with severe swallowing difficulties, continence and caring for wounds and leg ulcers. They might be able to help with rehabilitation exercises and arrange equipment like a wheelchair or alterations to your home.

Intermediate care

In some areas, intermediate care services are available (sometimes called early supported discharge). These are services to help a person return home from hospital sooner and continue their recovery at home, including rehabilitation therapies. The person should be able to continue any rehabilitation services such as physiotherapy, speech and language therapy and occupational therapy, and receive any personal care they need.

Before leaving hospital, the person you are caring for may be assessed for these services and a structured plan may be made with agreed goals and timescales for the therapists and patient to work towards.

Rehabilitation

If the person you are caring for does not receive intermediate care (early supported discharge), they may still be able to receive further rehabilitation once they are at home. Ask a member of the medical team at the hospital, or their GP, if they have already come home, about receiving rehabilitation they need after leaving hospital.

Community care

Community care services

These services may help with personal care (for example, getting in and out of bed, bathing, dressing), day care, meals on wheels and respite care. They often involve carers coming to your home to help with specific tasks.

Local authorities will usually only provide services for people who have the highest levels of need. They vary in what help they can offer and the person you care for may need to contribute to the cost.

Aids and adaptations

Your local authority can arrange for someone (usually an occupational therapist) to assess what aids or adaptations would make life easier at home such as grab rails or ramps. If major adaptations to their home are needed, the person can apply for a Disabled Facilities Grant. This is available through local authorities in England, Wales and Northern

Ireland. In Scotland, you can apply to the local authority's Scheme of Assistance for help with repairing and adapting housing if you have a disability.

Local support

You should be given information about local groups and services for people who have had a stroke and for you as a carer, such as day centres.

Respite care

Respite care (sometimes called short breaks) is designed to give carers a break. It could be:

- care at home from a trained care assistant or volunteer, for a few hours a week
- care outside the home, for example, at a day centre or social club
- longer breaks (from days to weeks) in a residential or nursing home.

The respite services offered vary widely, so ask your local authority about what is available in your area. Services may be provided by the NHS, social services, and voluntary or private organisations. If the person needing care is eligible for NHS respite care, it is usually free. Other respite care services may charge, or ask you to contribute towards the costs.

The cost of care services

Local authorities will usually only provide services for people who have the highest levels of need. They vary in what help they can offer and the person you care for may need to contribute to the cost. For more information see our guides F20, *Accommodation after stroke* and R09, *Aids and equipment for independent living*.

The charging for community care services is complicated. Local authorities can charge for some or all of the services they provide. There may be a flat rate for a service or it may be means tested, so they will ask about the person's income and savings and then charge according to a sliding scale. Free personal care is available for people aged over 65 in Scotland.

If you need advice about paying for community care services, speak to a specialist organisation like Citizens Advice or a carer's centre. Their contact details are listed in *Other sources of help and information* later in this guide.

Direct payments

If you (or the person you care for) have been assessed as needing support, it is your right to receive direct payments instead of services. This means your local authority will give you money directly so you can choose how to arrange your own services. This will give you more choice and control over the support you receive. For example, you can use the payments to help with taxi fares, a short holiday or help with housework.

Direct payments are voluntary so you do not have to have them if you would rather receive

services directly from your local council. Direct payments are available in the UK, and you apply to your local authority (or trust in Northern Ireland). You could become an employer if you pay someone to work for you, so you will need to learn about the responsibilities involved in this. Contact Carers UK (see *Other sources of help and information*) for more information about direct payments.

What if my situation changes?

A review of your care plan should take place once your loved one has returned home. You should be told when it will happen. If this does not happen or the person you are caring for was not admitted to hospital, contact your local authority and ask for a community care assessment.

Caring from a distance

Many families live away from the person who has had a stroke, and they may have significant family and work commitments. If it's only possible for you to provide occasional support, you should make it clear to the health professionals involved that you will continue to live apart from the person you are caring for, and that while you are involved in planning their return home, you will not be able to contribute to their day-by-day care.

If you are arranging ongoing care for a person after a stroke but live elsewhere, there are a few things that you might want to consider to help them at home. To improve safety in the home, install fire or smoke alarms, and door entry systems. You may want to consider a community alarm (a 24-hour phone link to the local emergency response centre). Ensure that the person

can easily find everything that they might need (for example, medications), and try using weekly planners.

Think about what aids and adaptations the person might need and take steps to reduce the risk of falls – social services should be able to advise you on these issues.

Legal matters

You may find that the person you are looking after has difficulty managing their affairs. He or she may be unable to sign cheques or use online banking, or may have difficulties in making or communicating their own decisions (sometimes referred to as a lack of mental capacity).

Ask the bank if they have any help to allow people with disabilities to access their services. This could include talking cash machines, large print bank statements, communication support in the branch or accessible debit cards.

If someone is unable to make their own decisions, they can appoint someone to have lasting power of attorney (LPA). This could be a family member, friend or carer. This nominated person would then be able to make decisions about their property and finances or their health and welfare, if they are unable to do so themselves in the future. You can appoint more than one person to have an LPA.

There are two types of LPA. A property and affairs LPA can make decisions about income, bills and the sale of a person's house. A personal welfare LPA can make decisions on where the person will live and the day-to-day care or medical treatment he or she may receive. In Northern Ireland there

is only one type of power of attorney, called an enduring power of attorney, which covers property and affairs, but not healthcare.

A person must be mentally well to set up a power of attorney. If the person you are caring for has already lost the ability to make decisions, you can apply to take over their finances. If you live in England or Wales, you apply to the Court of Protection to become a deputy. In Scotland, you apply to the Office of the Public Guardian (Scotland) to become a guardian. In Northern Ireland, you apply to the Office of Care and Protection to become a controller. The contact details of each are listed at the end of this guide.

Financial impact

If you're caring for someone you may be faced with higher heating bills and costly equipment or home alterations. Your loved one may have had to give up work because of their stroke, or you may be considering giving up work. Inevitably this will reduce your income and social contact.

It may help to consider reducing your hours, or finding a job nearer home. Some carers have the right to request flexible working hours, and though employers are not legally bound to agree, there must be a good business reason for saying no.

If you become a full-time carer, you may be entitled to claim Carer's Allowance. If you care for someone for at least 35 hours a week, you may be eligible. For information on how to apply, contact a carers' organisation or visit a carer's centre.

If you decide to give up work, check what help you are entitled to under your pension scheme (if you have one). If you are not

working or claiming Carer's Allowance, you may be able to claim Carer's Credit to help protect your state pension.

The benefits system is complex so seek specialist advice about what you are entitled to and help with filling in claim forms.

See our guide R01, *Benefits and financial assistance*.

What if my loved one can't come home?

Caring for the person affected by stroke at home may not be the best or most feasible solution. You might consider other options, such as sheltered housing (where a warden can look in regularly), or a care home. This may be a very difficult decision and not one that you will make lightly or quickly.

Your local authority will be able to provide an assessment, and information on care homes and funding available. Our guide F20, *Accommodation after stroke* may also be helpful.

Looking after yourself

A stroke can have a huge impact on the whole family. It is common for someone who has had a stroke to feel quite low upon returning home and to need a lot of encouragement. They may have less control over the small, everyday decisions many of us make without thinking – when to get out of bed, take a shower or phone a friend, and this can be difficult to cope with.

You and other family members may be faced with new roles and responsibilities. You may find yourself suddenly having to take over tasks such as cooking, housework

or managing the family finances because the person you care for can no longer do them. You may need to think about learning to drive, rearranging your home to make it safer, or even moving house.

You may need to help your loved one with a daily therapy routine or by finding new activities and pastimes for them. This may take up your time, but will be worth it in the long run.

Caring for someone is a huge responsibility. It is realistic, not selfish, to think carefully about taking care of yourself. If you don't look after yourself, you risk becoming stressed or exhausted and this could also affect the person you are caring for.

When your loved one first comes home, keep a diary for a week. This may help you establish what help or support you need. Social services should review the situation from time to time to see whether your needs have changed, but if your situation changes, ask for a review straight away.

Back strain is a common problem caused by moving someone. A community or district nurse or occupational therapist can teach you how to help someone move safely so you don't strain your back. They may also be able to show you relaxation techniques to help with tiredness or stress. Your local carers' centre may offer classes to overcome these issues. A gentle exercise routine that gets you out of the house can increase your energy levels and help you feel more positive.

It's important to recognise if you're feeling tired or depressed. Taking regular breaks is crucial. This might involve having a few hours to yourself every day or arranging

more formal respite care. Try to organise the day so that you have at least a little time to yourself. Ask family members or friends for help with specific tasks, if you need it. You may also want to find a local carers' support group to meet others in the same position as you.

A carers' centre or organisation can offer advice, information and practical support in your area. You can find their details by contacting our Stroke Helpline, social services, your GP, or the hospital where the person you are caring for was treated after their stroke.

Many carers can feel socially isolated. Friends may avoid contact because they are not sure how to behave towards someone who has had a stroke. You may also worry about leaving the person you are caring for alone whilst you socialise with people. Try to keep in touch with others. While some friendships may fade away, you can build up new ones with people who share your interests. Stroke clubs and carers' groups can be a good starting point. Contact our Stroke Helpline for details.

Tips to help recovery

Many carers ask us how they can help the person they are caring for to recover. Becoming a carer and supporting your loved one is a great start to making them feel independent again. Here are some suggestions that may help.

- Ask for guidance from the professionals who have played a major role in your loved one's recovery. Their input will help you.
- Encourage the person to take on family responsibilities right from the start. You may need to find new roles that are manageable to help to boost their confidence and maintain their relationships with other family members.
- Try not to be overprotective. You need to find the right balance between helping the person you care for and developing their independence. Encourage them to do as much as they can, right from the start. This may be a very slow process and can be frustrating at first, but in the long run it is the best way to help someone.
- Be patient. Stroke damages the brain, which can make it difficult to relearn even simple tasks.
- Set up a daily routine that works for both of you. This may take time, but will be worth it. Think about the daily tasks that the person can either do independently, can start to relearn or will need help with. Plot the time that each task will take then draw up a list of small steps towards relearning some of the missing skills. Build in short, but frequent, periods in the day to practise movements, exercises and skills.
- Be positive. Recovering from stroke is a slow process and so your praise is needed for every sign of progress, however small. Reassure the person that you are caring for that things can get better, especially when progress seems slow.

Where to get help and information

From the Stroke Association

Talk to us

Our Stroke Helpline is for anyone affected by a stroke, including family, friends and carers. The Helpline can give you information and support on any aspect of stroke.

Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100** or email **info@stroke.org.uk**.

Read our publications

We publish detailed information about a wide range of stroke topics including reducing your risk of a stroke and rehabilitation. Read online at **stroke.org.uk** or call the Helpline to ask for printed copies.

Other sources of help and information

Useful organisations for carers

NHS: Your guide to care and support

Website: www.nhs.uk/care-and-support
Carers Direct (England only):

0300 123 1053

Has detailed information on a range of care and support issues. The Carers Direct helpline provides specialist information related to your own personal support needs as well as the needs of whoever you are caring for.

Carers UK

Website: www.carersuk.org

Tel:

0808 808 7777 (England, Scotland and Wales)
0289 043 9843 (Northern Ireland)

Offers information and support for carers, including information about finances and benefits.

Carers Trust

Website: www.carers.org

Tel: 0844 800 4361

Provide information, advice, training, education and job opportunities for carers. They give details of your nearest carers' centre, and also provide respite care in England and Wales.

Crossroads Care NI

Website: www.crossroadscare.co.uk

Tel: 028 9181 4455

Crossroads Caring Scotland

Website: www.crossroads-scotland.co.uk

Tel: 0141 226 3793

Provides respite care, as well as support for carers and those who they care for.

Other useful organisations

Age UK

Website: www.ageuk.org.uk

Advice Line:

0800 055 6112 (England)
0888 470 8090 (Northern Ireland)
0800 124 4222 (Scotland)
0800 169 6565 (Wales)

Provides useful advice for older people including benefits and advice for carers.

British Bankers' Association

Website: www.bba.org.uk

The UK banking and financial services trade association. Publishes a range of leaflets that give advice on financial matters.

Citizens Advice

Website: www.citizensadvice.org.uk

Offers advice and information on a range of issues including debt, benefits, legal issues and housing.

Contact a Family

Website: www.cafamily.org.uk

Tel: 0808 808 3555

Offers advice and support for families with disabled children.

Disability Rights UK

Website: www.disabilityrightsuk.org

Tel: 020 7250 8181

Provides information about benefits, tax credits and social care charges. Publishes the Disability Rights Handbook.

Headway

Website: www.headway.org.uk

Tel: 0808 800 2244

Serves people with acquired brain injury, as well as their families and carers through a UK network of Headway House centres and local groups.

Independent Age

Website: www.independentage.org

Tel: 0800 319 6789

Advice and information for older people, their relatives and carers.

Legal matters

Court of protection

Tel: 0300 456 4600

Website: www.gov.uk/court-of-protection

Offers information on becoming a deputy.

Office of the Public Guardian (England and Wales)

Tel: 0300 456 0300

Website: www.gov.uk/opg

Office of the Public Guardian Scotland

Tel: 01324 678 300

Website:

www.publicguardian-scotland.gov.uk

Offers support for those who lack capacity or would like to plan for their future. Has information on power of attorney.

Office of Care and Protection (Northern Ireland)

Tel: 0300 200 7812

Website: www.courtsni.gov.uk

Offers support for those who lack capacity or would like to plan for their future.

UK Government: power of attorney

Tel: 0300 456 0300

Website: www.gov.uk/power-of-attorney

Offers information on power of attorney and becoming a deputy through the court of protection.

Keeping in touch

At the Stroke Association, we understand that the impact of a stroke can turn everything upside down in an instant, not just for the stroke survivor but for their loved ones too.

We are proud to be the leading stroke charity in the UK, changing the world for people affected by stroke. As you may know, our vital work covers many areas, including providing support and information to stroke survivors and their families, funding research into stroke treatment and care, and campaigning to raise awareness of stroke.

We are determined to conquer stroke, but we cannot do it alone.

Keep in touch and find out more about our work. This includes groundbreaking research developments, other services that might benefit you and opportunities to get involved with appeals, campaigns or volunteering for the Stroke Association.

To keep in touch, either fill out our online contact form at stroke.org.uk/signup or complete your details below and send them to our freepost address:

Freepost RSZL-SAUL-GRBK
Keeping in touch
Life After Stroke Centre
Church Lane
Bromsgrove
Worcestershire B61 8RA

Your contact details

I am a:

- stroke survivor family/friend
 carer other

First name:

Surname:

Address:

Town/city:

County:

Postcode:

Email:

Telephone number:

I would like to receive Stroke News:

- online (we'll email you to let you know when an online copy is available)
 by post (we'll send you a free copy)
 I'm happy for the Stroke Association to keep in touch with news updates and ways to get involved

I'm happy to be contacted by:

(please tick all that apply)

- post telephone email

You can change or stop the way we contact you at any time by calling our friendly Supporter Care team on **0300 330 0740**, or by emailing supportercare@stroke.org.uk.

About our information

We want to provide the best information for people affected by stroke. That's why we ask stroke survivors and their families, as well as medical experts, to help us put our publications together.

How did we do?

To tell us what you think of this guide, or to request a list of the sources we used to create it, email us at feedback@stroke.org.uk.

Accessible formats

Visit our website if you need this information in audio, large print or braille.

Always get individual advice

Please be aware that this information is not intended as a substitute for specialist professional advice tailored to your situation. We strive to ensure that the content we provide is accurate and up-to-date, but information can change over time. So far as is permitted by law, the Stroke Association does not accept any liability in relation to the use of the information in this publication, or any third-party information or websites included or referred to.

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We rely on your support to fund life-saving research and vital services for people affected by stroke. Join the fight against stroke now at stroke.org.uk/fundraising
Together we can conquer stroke.

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).