

Stroke: A carer's guide

When someone close to you has had a stroke, they may need ongoing help and support after they return home from hospital. This factsheet aims to provide you with guidance if you are caring for a stroke survivor at home. It outlines some ways to help you in your new role, and explains what help and support is available.

What is a carer?

A carer is someone who provides **unpaid support to family or friends** who could not manage without this support. One in 10 people in the UK is a carer. Often people do not choose to become carers, it just happens, and 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 have told us that they 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-to-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 in between therapy sessions, such as helping your loved one relearn 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 the 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**. These include problems with mobility, swallowing, continence, vision, communication, tiredness, memory and concentration. It can also affect emotions and can cause depression, anxiety or personality changes. These changes can have a big impact on everyone.

You may feel a deep sense of loss as the person you know and love may not 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

Recovery from stroke is difficult to predict, so planning for the future can be hard. The

amount of recovery someone will make and the amount of time it takes varies. Recovery may take several weeks or months, and it 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, however, will improve only a little and may need substantial community or 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**. You may have already been their carer, but the effects of the stroke may have changed the amount of care they need.

Caring for someone can take up a lot of energy and requires perseverance so it should not be undertaken lightly. It may be helpful to **talk to someone** before you make a decision about becoming a carer. You can call our Stroke Helpline, or contact one of the carers' charities (see *Useful organisations*).

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 **community care assessment** for your loved one to determine what support they need, and a **carer's assessment** of your needs.

Carer's assessment

If you are going to be a carer, you have a right to have an assessment for your needs to be considered. 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 social services, will carry out your assessment. They will look at your role as a carer and the affect 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 in hospital 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.

Community 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. 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.

Community or district nurses may also help with rehabilitation exercises, arrange equipment such as a wheelchair, commode or hoist, or give advice on arranging your home to make caring easier.

Intermediate care

In some areas, intermediate care services are available (sometimes called early supported discharge). These are **services to help someone return home sooner and become as independent as possible**. They can include community rehabilitation services such as physiotherapy, speech and language therapy and occupational therapy as well as personal care, given to the person at home rather than in hospital.

Before they leave 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 to work towards.

Rehabilitation

If the person you are caring for does not receive intermediate care, they may still be able to receive further rehabilitation once they are at home. **Community rehabilitation services** can include speech and language therapy, physiotherapy and

occupational therapy. Ask a member of the medical team at the hospital, or their GP, if they have already come home, about receiving rehabilitation at home.

Community care

Community care services

These services may help with **personal care** (for example, getting in and out of bed, bathing or 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 from their local authority (England), Care and Repair (Wales) or the Northern Ireland Housing Executive. In Scotland the Home Improvement and Repair Grant scheme applies.

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 a day centre that the person you care for can attend.

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, or
- 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, 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

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 the Citizens Advice Bureau or a carers' centre. Their contact details are listed in the *Useful organisations* section.

Direct payments

If you (or the person you care for) have been assessed as having needs, **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 throughout the UK but there are slight differences in the way the scheme works in different countries. Contact Carers UK (see *Useful organisations*) for more information.

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 and how frequently 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-to-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. Install **fire or smoke alarms** or 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, medication), and try using weekly planners, placing them where they can easily be seen.

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. See our resource sheet *R3, Aids and equipment for independent living* for more information.

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 may have difficulties in making or communicating their own decisions (sometimes referred to as a lack of mental capacity).

If they have physical difficulties, using an adapted pen and a clipboard or non-slip mat, or a credit/debit card template may help to produce a consistent signature. Ask their bank if they have any templates. In England and Wales, a facsimile stamp (rubber stamp) may also be used. For more information contact the British Bankers Association (see *Useful organisations*).

When the effects of stroke are more complicated and include problems with memory, thinking and understanding, legal powers may be needed.

If someone is unable to make their own decisions, they can appoint someone to have **Lasting Power of Attorney (LPA)** for them. 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, in the future, they are unable to do so themselves. You can appoint more than one person to have an LPA for you.

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, the second type, 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 able to make their own decisions 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 and become a 'deputy'**. This is a different process. If you live in England or Wales, you apply to the Court of Protection. In Scotland, you apply to the Scottish Office of the Public Guardian. In Northern Ireland, you apply to the Office for Care and Protection. The contact details of each are listed at the end of this factsheet.

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 working 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. See Carers UK's booklet *Carers and employment: a guide to the right to request flexible working* for more information.

If you become a full-time carer, you may be entitled to claim **Carer's Allowance**. You can claim this if the person you are caring for is receiving Attendance Allowance or the higher or middle care component of Disability Living Allowance (Personal Independence Payment from 2013/14). It is a means-tested benefit and so will depend on any other money you have coming in.

If you decide to give up work, check if you are entitled to any help from 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. Contact Carers UK for more details.

The benefits system is complex so seek specialist advice about what you are entitled to and for help with filling in claim forms. See the *Useful organisations* section and our resource sheet *R1, Benefits and financial assistance* for more information.

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 to make and not one that you will make lightly or quickly. Contact a carers' organisation or see the booklet *When caring comes to an end* by Carers UK and Help the Hospices for more information.

Your local authority will be able to provide an assessment and information on care homes and funding available. Our factsheet *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 on 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 also 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 who is dependent on you 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 your situation from time to time to see whether your needs have changed, but **if your situation changes, ask for a review straightaway**.

Back strain is a common problem caused by lifting or moving someone. A community or district nurse or physiotherapist can teach you how to move someone 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 help you manage 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 is important to recognise if you're feeling **tired or depressed**. Taking regular breaks is crucial. You might consider 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 join 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 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 are a good starting point. Contact us 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 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 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. Think about the daily tasks that the person can 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.

Useful organisations

All organisations are UK wide unless otherwise stated.

Stroke Association

Helpline: 0303 30 33 100

Email: info@stroke.org.uk

Website: stroke.org.uk

Contact us for information about stroke, emotional support and details of local services and support groups.

Useful organisations for carers

Carers Direct (NHS) (England and Wales)

Helpline: 0808 802 0202

Website: www.nhs.uk/carersdirect

Detailed information for carers.

Carers UK

Tel: 0808 808 7777

Website: www.carersuk.org

Carers Northern Ireland

Tel: 028 9043 9843

Website: www.carersni.org

Carers Scotland

Tel: 0141 445 3070

Website: www.carersscotland.org

Carers Wales

Tel: 029 2081 1370

Website: www.carerswales.org

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

Carers Trust

Tel: 0844 800 4361

Website: www.carers.org

Crossroads Care and The Princess Royal Trust for Carers have merged to form the Carers Trust. They can give you details of your nearest carers' centre. They also provide respite care (England and Wales), information, advice, training, education and job opportunities.

Crossroads Caring for Carers

(Northern Ireland)

Tel: 028 9181 4455

Website: www.crossroadscare.co.uk

Crossroads Caring Scotland

Tel: 0141 226 3793

Website: www.crossroads-scotland.co.uk

Provide respite care.

Other useful organisations

Age UK

(formerly Age Concern and Help the Aged)

Age UK Advice: 0800 169 65 65

Website: www.ageuk.org.uk

Age Cymru: 0800 169 65 65

Website: www.agecymru.org.uk

Age NI: 0808 808 7575

Website: www.ageni.org.uk

Age Scotland: 0845 125 9732

Website: www.agescotland.org.uk

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

Benefit Enquiry Line (BEL)

(England, Scotland and Wales)

Tel: 0800 88 22 00

(Northern Ireland)

Tel: 0800 220 674

Provide information and advice on benefits, personal benefit calculations and phone completion of Attendance Allowance, Disability Living Allowance and Carer's Allowance claim forms.

British Bankers' Association

Website: www.bba.org.uk

The UK banking and financial services trade association. Publishes a range of leaflets.

Contact a Family

Tel: 0808 808 3555

Website: www.cafamily.org.uk

Support for parents of all disabled children.

Citizens Advice Bureau (CAB)

Website: www.adviceguide.org.uk

See their website to find details of your local bureau or look in your local telephone directory.

Website: www.citizensadvice.org.uk

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

Counsel and Care

Tel: 0845 300 7585

Website: www.counselandcare.org.uk

Advice and information for older people,

their relatives and carers.

Disability Alliance

Tel: 020 7247 8776

Website: www.disabilityalliance.org

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

Headway – the Brain Injury Association

Tel: 0808 800 2244

Website: www.headway.org.uk

Serves people with acquired brain injury, their family and carers through a UK network of centres and local groups.

National Centre for Independent Living

Advice line: 0845 026 4748

Website: www.ncil.org.uk

Information and advice on independent living and direct payments for disabled people.

Legal matters

Office of the Public Guardian (England and Wales)

Tel: 0845 330 2900

Website: www.publicguardian.gov.uk
(Scotland)

Tel: 01324 678300

Website: www.public-guardian-scotland.gov.uk

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

Has information on becoming a Power of Attorney.

Office for Care and Protection (Northern Ireland)

Tel: 028 9072 4733

Website: www.courtsni.gov.uk

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

Court of Protection (England and Wales)

Tel: 0300 456 4600

Offers information on becoming a deputy.

Government website (England and Wales)

Website: www.gov.uk

(Northern Ireland)

Website: www.nidirect.gov.uk

Offers information on Power of Attorney and becoming a deputy through the court of protection.

Disclaimer: The Stroke Association provides the details of other organisations for information only. Inclusion in this factsheet does not constitute a recommendation or endorsement.

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For sources used, visit stroke.org.uk

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