

A close-up photograph of a hand holding another hand, symbolizing care and support. The background is blurred, showing green foliage and a light-colored surface. The image is framed by a green diagonal line at the top and a white diagonal line at the bottom, with a blue and green geometric shape at the bottom left.

Information
Pack

Caring for somebody after a stroke

Reclaiming lives after stroke

Who Is This Booklet For?

This booklet aims to give you help and guidance after your stroke. It explains what a stroke is and why they occur; it lets you know what to expect in the future; and explains how you can learn to live with your symptoms give you help and guidance after your stroke.

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<h3>Do you have any questions?</h3>	
	<p>Contact us on our information line to obtain practical information on life after stroke and signposting.</p> <p>Information Line</p> <p>0345 130 7172 or 01908 317618</p>
<p>Write to us:</p>	<p>9 Canon Harnett Court Wolverton Mill Milton Keynes MK12 5NF</p>
<p>Email us:</p>	<p>info@differentstrokes.co.uk</p>
<p>Visit our website:</p>	<p>www.differentstrokes.co.uk</p>
 Follow us on Facebook	<p>www.facebook.com/differentstrokescharity</p>
 Join us on Facebook	<p>Apply to join our Facebook support group if you are a working age stroke survivor</p> <p>www.facebook.com/groups/differentstrokesuk (Private group, your friends and family won't be able to see what you post)</p>
 Follow us on Twitter	<p>@diffstrokes</p>
 Follow us on Pinterest	<p>Pinterest: www.pinterest.co.uk/diffstrokes</p>

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This booklet is split into different sections and you may find that not all of it applies to you. It is worth keeping as a reference tool.

You may also find that some parts become more useful as your situation changes in the future.

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1. Introduction

Stroke often hits suddenly and without warning.

It can be especially devastating for younger people: one day fit and well, the next moment disabled, often with a young family to care for and support, and relying on employment for income rather than a pension.



Its impact is far reaching and affects not only the stroke survivor, but those all around, particularly close family and/or friends.

It can lead to immediate and often longer-term changes in roles.

As somebody whose loved one has suffered a stroke, you may find that your whole life is disrupted and thrown upside down, and then you may find yourself unexpectedly in the role of carer with very little time to adjust to your new circumstances.

This can be a tiring and demanding role at a time of high stress. You may feel unprepared to take on this role and to be responsible for another person and it may lead to a daunting role reversal in your family set-up, requiring you to give up your income and independence.

"I think, because I'm not earning what I used to earn, that's my fault I think -



I should be out there earning what we used to earn, but mentally I couldn't do it and that's a big burden on her.

And I don't see why she should have to worry about everything, although I don't say it to her."

Stroke Survivor

Caring for someone you love can be one of the most important and difficult jobs a person can do.

At times though, it may be normal to feel sad, angry, tired, frustrated, depressed, under-valued and even lonely.

On the other hand, caring may also be rewarding and fulfilling if you learn to pace yourself, seek help when you need it, and remember to take care of yourself too!

"I've actually found that our marriage has been stronger since my husband had his stroke. It's hard work at times but we work through things".

Wife

Younger stroke survivors and their families need immediate, relevant and practical information and advice to:

- take control of their lives
- optimize their recovery
- regain as much independence as possible and
- play a full role in their communities.

In the initial time period after the stroke however, you may find there is simply too much to take in, at a time when others are additionally turning to you for support. You may feel pulled in all directions.

As well as the emotional distress at witnessing what has happened to your loved one, it is natural to feel overwhelmed by the sheer volume of information you are being given and to struggle with the practical arrangements you have to deal with.

Even if you can't take it all in straight away, or don't think you'll need it, it's a good idea to keep hold of all the information and useful contacts you are offered.

Your needs and those of the person you care for are bound to change over time, and it is worthwhile to have resources for the longer term.

One of the primary concerns is what level of recovery the person might make. Recovering from a stroke is a gradual process, taking weeks or months, but often continuing for many years.

Some people make an almost full recovery. Most recover enough to be independent in most aspects of daily living; they are able to do many of the things they did before, perhaps with some support. Some, however, will improve only a little and need long-term care.

Medics often err on the side of caution with regards to their predictions for the future – it is important to try to keep positive and to focus on the continuing signs of recovery, however minor they may seem at the time.

Keeping a diary of achievements is a good way of being able to chart progress to remind you that improvements are occurring.

The stroke survivor's needs with regard to ongoing rehabilitation should be assessed before discharge from hospital and a care plan should be devised. Hospitals should also be able to provide the stroke survivor and /or carer with a written statement that describes the services being given.

2. At Home Again

When someone close to you has a stroke, they may need extra help and support during their recovery, which often continues after they return home. Knowing who to speak to if services are required is very important.

Families struck by stroke often say the full impact of their situation hits them once the stroke survivor leaves hospital and they attempt to renegotiate their daily lives.

For some, this can feel like a time of abandonment, when it is hard to know how to access help and advice. Asking the hospital to draw up a structured plan for how continued rehab will work in the home environment may help to ease the transition back into home life.

"I'd have liked to have been there a bit, a few more times, to see the whole physio process so that when she did come out of hospital I could've made sure she carried on with it or done something similar and not push her too far or not push her hard enough"

Daughter

Be prepared, if necessary, to push for the rehabilitation services that you feel the stroke survivor requires. Services such as physiotherapy, occupational therapy, speech and language therapy and psychological support can be vital in getting the stroke survivor up and about and on the road to recovery. If the stroke survivor is not referred to these services on a hospital outpatient basis, ask your GP about services in your area and ask for a referral to the appropriate professional.

Caring for someone may also involve extra expense – for example, taking time off work or paying someone to help with caring, larger heating bills, extra equipment, contributing towards some of the support services or perhaps alterations to the home.

If you are working, you may consider stopping work. However, think through the implications carefully before reaching any decision. Giving up your job is likely to mean a drop in income when you most need it and less social contact outside the home. It is worth considering alternatives, such as asking to take some leave, reducing the hours you work, or perhaps finding a job nearer home.

If you are thinking of giving up your job, it may help to make an appointment with a Welfare Rights Officer for a “Benefits Check” to find out what benefits and financial assistance you’ll be entitled to in this instance. Contact your Citizens Advice Bureau, Dial UK or local library to see who provides this service in your local area.

If your partner is unable to continue working, you may be entitled to financial assistance – contact the Different Strokes office and request a copy of our “Benefits” info. Also ask for a copy of the leaflet detailing “Charities That May Be Able To Assist Financially.”

“I used to help her wash and bathe, cut nails. I used to be there for her when she wanted to shout and bawl at someone. I used to be able to let her cry. Anything she needed doing I’d make sure I was around to do it”.

Daughter

“She was the mum and I was the child... she wasn't just the mum she was the nurse, the carer, my best friend ... she put her life on hold for me”

Stroke Survivor

Becoming a Full-Time Carer

Depending on your circumstances, you may decide to become a full-time carer. If you are caring for someone for at least 35 hours a week who receives Disability Living Allowance or PIP at the middle or highest rate for personal care, you may be entitled to receive Carers Allowance of £59.75 per week which will help meet some of the extra costs.

If you give up work, check if you are entitled to any help under your pension scheme or whether you can protect your pension rights.

Direct Payments which allow people to arrange their own care are often more appropriate for younger stroke survivors, and help to achieve a balance between basic necessities and wider goals.

Your Social Services department will be able to provide an assessment, and information on the funding available through your local authority. There is a complaints procedure to use if you are dissatisfied with any aspect of the service. The Social Services department also has registration details of care homes and care homes with nursing in your area.



1.

3. Carer's Direct -Online Resource & Telephone Advice



Carers Direct

Information, advice and support for carers

2.

Carers Direct is an online information service (part of NHS Choices) which aims to provide an online resource to help carers manage their lives around caring. It can be found at: **www.nhs.uk/Carersdirect**.

It includes guidance on:

- the different stages of caring
- information for claiming benefits
- contact details for local authorities, as well as contact details for specialist, national and local sources of support.

There is also a free helpline on 0808 802 0202 (9am to 8pm Monday to Friday and 11am to 4pm at weekends). It provides information on assessments, benefits, direct payments, individual budgets, time off, and combining work or education with caring.

Carers (Recognition and Services) Act 1995

If you find yourself in the position of full-time carer, help and information is available. If you are going to provide a substantial amount of care, you have a right to a separate assessment of your own 'ability to care' under the Carers (Recognition and Services) Act 1995. Under this particular act, carers can ask for their views – and any needs or difficulties in coping with caring – to be taken into account when deciding what services will be provided. The Carers (Equal Opportunities) Act builds on existing legislation and support for carers by:

- placing a duty on local authorities to ensure that all carers know that they are entitled to an assessment of their need
- placing a duty on councils to consider a carer's outside interests (work, study or leisure) when carrying out an assessment
- promoting better joint working between councils and the health service to ensure support for carers is delivered in a coherent manner

This assessment is about your needs as a carer. The needs of the person you are caring for should be discussed in their own needs assessment. If this does not happen or the person was not admitted to hospital, contact social services directly to ask for an assessment. People with disabilities have a legal right to an assessment (Section 4 of the Disabled Person's Act 1986, reinforced by Section 47 of the NHS and Community Care Act 1990).

Social services will develop a 'care plan' based on your care assessment and the community care assessment of the person you care for. This plan should include the support and services that you have been assessed as needing. After the assessment your local council will look at your income and capital (savings and property) to decide which care services - if any - you may be charged for. Your right to an assessment, and to the services and support you may receive, is not linked to your income or capital.

4. Stroke and the family



A stroke is a shock to everyone. Partners and family members often feel a deep sense of loss, because the stroke changes the person they know and love. In the early days, it is often not possible to predict how much an individual will recover or what level of care will be needed.

Becoming a carer may mean reorganising your whole life and losing your former independence and/or income. Many carers go through feelings of loss and grief for the way that their life and that of the person they care for has changed.

"I think with partners, some people find it very very difficult to cope with illnesses or disabilities and so they just move on from there 'cause they can't handle it"

Stroke Survivor

"I didn't want to burden her with me and my ailments for the rest of her life... in fact I think I pushed her away to be honest, more than anything else... so we split up."

Stroke Survivor

Caring may be difficult and stressful at times. It is not unusual to have feelings of anger, resentment, guilt, anxiety or depression – or all of these at different times. Finding someone to talk to about how you feel can help.

Use the Different Strokes group on Facebook to make contact with other carers, share experiences and feelings

A stroke is likely to change the lives of the entire family in many different ways. 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.

"I had no outside help at all... it put a tremendous strain on my wife having to cope alone as well... then we were told about the help we could get and I should contact the various health people – my wife started to do all of this, and keep a full time job down – it has been very hard on her and with the way I am it does not help".

Stroke Survivor

- The stroke may have left the stroke survivor with a variety of physical complications, such as problems with continence, communication or mobility.
- A stroke can also cause psychological or emotional changes, which may be more difficult to cope with. Common changes include depression, tiredness, memory problems, loss of concentration, personality changes or irritability.
- It is important to realise that these changes are the result of the stroke and that the stroke survivor has no control over them.

5. Helping yourself



Caring for someone who is dependent on you is a big responsibility. It is realistic, not selfish, to think carefully about taking care of your own health and organising support for yourself. If you don't look after yourself, you may risk becoming so stressed or exhausted that you are no longer able to care for the person who has had a stroke.

Relaxation techniques may help to deal with tiredness or stress. A gentle exercise routine that gets you out of the house can increase your energy levels and help you feel more positive.

Tiredness and depression may also become issues. Taking regular breaks is crucial. 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.

It is also worth finding out if there is a carers' support worker or carers' centre offering advice, information and practical support in your area. Try not to "bottle up" your feelings – remember you can use the Different Strokes group on Facebook to talk about your feelings. You can also call the Stroke Line on 0845 130 7172, Monday to Friday from 9am to 5pm.

Respite Care

If you are providing full-time care, you may be entitled to “respite care”- services which are designed to provide a break for you by providing care in the home for the stroke survivor from a trained care assistant or volunteer for a few hours a week. It may also involve providing care outside of the home on an occasional basis for the stroke



survivors for a few days to a couple of weeks in a residential or nursing home.

Respite services vary widely around the country, so ask social services 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.

6. Tips for carers

➤ **Try to be as positive as possible.**

Rehabilitation after a stroke is a slow process and it is often common for someone who has had a stroke to feel quite low on returning home. They may need a lot of encouragement, so praise every sign of progress, however small. This may be difficult at times.

➤ **Be aware that bouts of depression can be common after stroke –**

encourage the stroke survivor to seek support or referral to a counsellor via the GP if they are affected. Likewise you may find it useful to talk through feelings with a counsellor or psychologist. Both of you may find it helpful to make contact with other Different Strokes members via one of our regional groups or the Different Strokes group on Facebook.

➤ **Try not to be too overprotective.**

This may be an understandable and even subconscious reaction, out of fear for the stroke survivor's safety or because you think doing too much will bring on another stroke. Try to get the balance right between helping and encouraging independence. Doing too much for the stroke survivor can be frustrating and can hold back recovery and sap confidence. Encourage your partner to do as much as he or she is able right from the start. This may be a gradual process of small steps at a time, but in the long run it will help the person relearn skills and regain confidence and independence.

➤ **Be patient.**

Stroke causes physical damage to the brain, which can make it difficult to relearn the simplest tasks. It can affect control of balance and movement but may also affect cognitive skills leading to problems with attention, concentration and memory. It can also affect confidence and self-esteem.

➤ **You may find it helpful to set up a daily routine.**

Think about the necessary daily tasks that the stroke survivor can either do independently, can begin to relearn, or may need help with. 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.

➤ **Build up your social life.**

Many people who have had a stroke feel embarrassed about any weakness or speech difficulties, and may feel reluctant to see friends or to go out. Friends may avoid contact because they are not sure what to say or how to behave towards someone who has had a stroke. Try to work out ways of rebuilding your social life so that you continue to see friends and go out together, if possible. Accept that some friendships may fade away. You may need to build up new ones with people who share your interests. Different Strokes groups and carers' groups can be a good starting point.

➤ **Try to give constant reassurance that things will get better,**

especially during periods when progress seems slow. It may be helpful to encourage the stroke survivor to keep a diary, or keep one on their behalf if easier, to chart achievements and to monitor progress.

7. Further Information

			
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