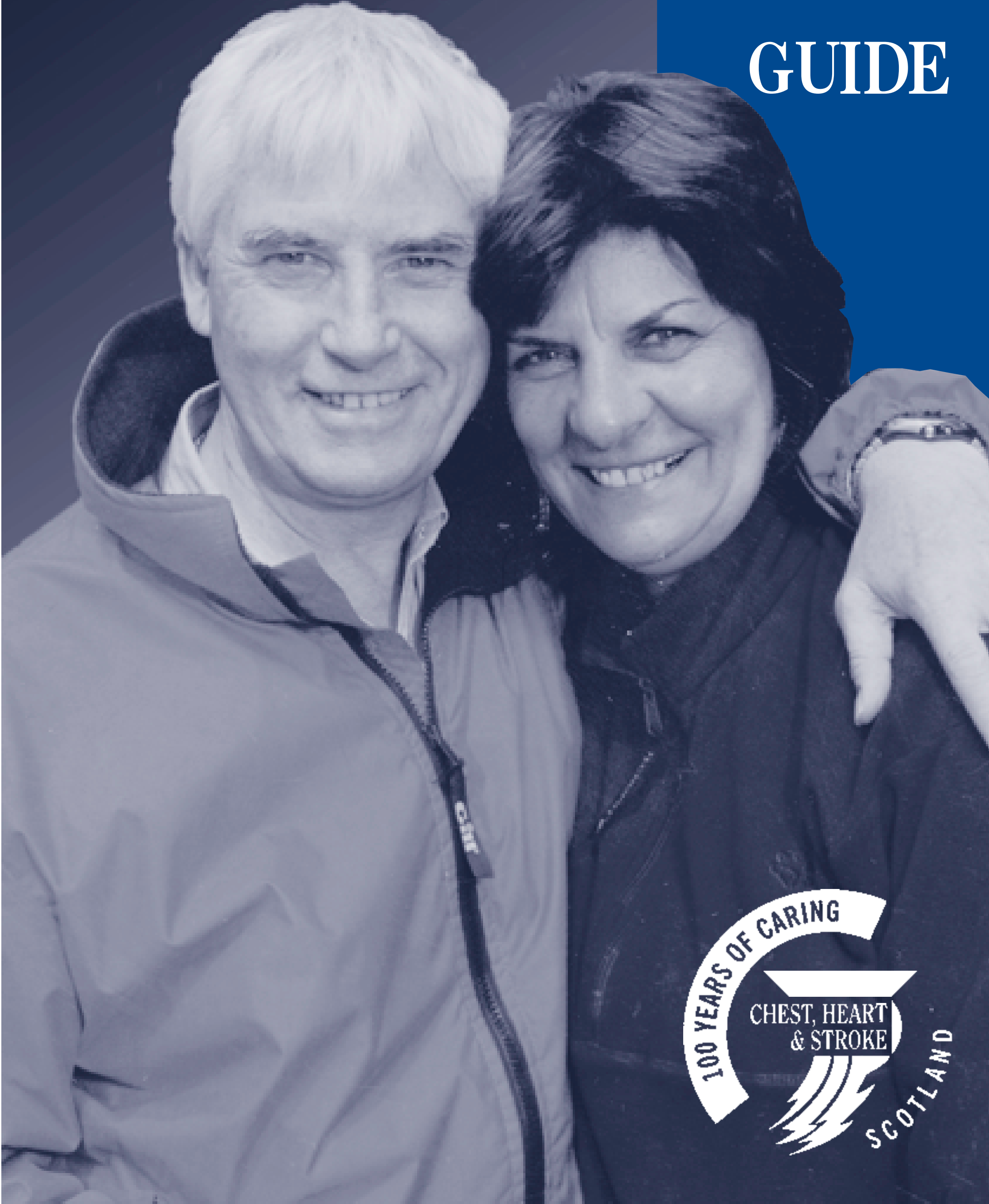
STROKE SERIES SS2

STROKE: A CARERS GUIDE



100 YEARS OF CARING

CHEST, HEART & STROKE

SCOTLAND

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& STROKE
SCOTLAND

Chest, Heart & Stroke Scotland, is an independent medical charity which aims to improve the quality of life for people in Scotland affected by chest, heart and stroke illnesses, through medical research, advice and information and support in the community.

FUNDRAISING

CHSS is an independent Scottish medical charity. We receive no Government funding and rely entirely on the Scottish public to raise the £3 million a year we need to help people with chest, heart and stroke illness throughout Scotland.

RESEARCH

We are one of Scotland's largest charitable funders of medical research, with a programme worth over £500,000 a year. We fund research projects throughout Scotland into all aspects of the prevention, diagnosis, treatment and social impact of chest, heart and stroke illness. If you would like more details, please call (0131) 225 6963 for an explanatory leaflet.

WELFARE

We provide small grants to people in financial difficulty because of chest, heart or stroke illness, for items ranging from clothing and bedding, to respite care. Applications are submitted through local Social Work Departments, or health professionals; for further information call (0131) 225 6963.

VOLUNTEER STROKE SERVICE (VSS)

We give practical help to people whose communication skills are impaired after a stroke. The VSS provides weekly group meetings and home visits for patients. For details ask for our VSS leaflet and Stroke Directory.

CHSS NURSES

Our nurses provide independent practical advice and support to those who have chest, heart and stroke illnesses, their families, carers and health professionals. There are dedicated nursing services in Fife, Glasgow, Grampian, Highland, Lanarkshire and Lothian. There is also a Scotland wide nurse led Advice Line (0845) 077 6000 calls are charged at a local call rate (out of hours answerphone). We have a wide range of booklets, factsheets and videos on chest, heart and stroke illnesses, which help towards an understanding of these conditions. Please ask for our publication list.

COMMUNITY SUPPORT NETWORK

CHSS provides support to affiliated chest, heart and stroke clubs through the Community Support Network. The clubs are independent and are run by local volunteers. The groups provide a range of activities and offer people support, stimulation and companionship in a friendly and relaxed environment. Please ask for the Group Directory for more information.

STROKE: A CARERS GUIDE

INTRODUCTION

In Scotland at any one time, there are 100.000 people who have had a stroke living at home. Most strokes occur in later life though younger men and women have them too. A stroke affects everyone differently, but they all rely heavily on the support of those around them - and especially on the help of close relatives and friends.

Who is a carer?

If you are a partner, relative or friend of someone who has had a stroke, and involved in their care, this booklet is for you. You may not think of yourself as a ‘carer’, but caring for someone after a stroke is a serious undertaking. Carers, whatever their age or circumstances, need information, practical help and support in their own right. Your encouragement and support, combined with the right professional guidance, can make a difference to the level of recovery of the person you care for.

How to use this booklet

It is unlikely that everything in this booklet will apply to you, so pick out the parts that you find most useful at the time. For many people, there are three particularly difficult times:

- the onset of the stroke and its immediate aftermath,
- discharge from hospital and adjusting to life at home
- the end of hospital and rehabilitation support – when people can feel unsupported and isolated.

Chest Heart and Stroke Scotland (CHSS) have several booklets and fact sheets that provide information about the recovery of the individual you care for. This booklet should be used in conjunction with **'Stroke: a guide to your recovery.'**

There is a full list of the stroke series on the back cover of the booklet.

Emotional effects on the family

There is a lot to take in, in the first few weeks after a stroke. On top of the emotional distress, many carers feel overwhelmed by the volume of information and practical arrangements that they have to deal with. Even if you can't take it all in straightaway, or don't think you'll need it, keep hold of all the information and useful contacts you are offered. Your needs and those of the person you care for are going to change over time.

Sense of loss

A stroke is a shock to the whole family. Partners and family members often feel a deep sense of loss, because the stroke changes the person they knew and loved. 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.

Caring is difficult and stressful. It is not unusual to have feelings of anger, resentment, guilt, anxiety or depression – or all of these at different times. These difficult feelings are the result of doing a very difficult job.

In the early days it is often not possible to predict just how much an individual will recover, or what level of care will be needed. Becoming a carer may mean reorganising your life, and losing your former independence and income.

Simple steps

At the beginning many people cope by getting by one day at a time, but this is not a basis for long-term care. Experienced carers say the most important things are to:

- get information about what services and support are available
- sort out practical help with the daily routine
- be flexible
- get a regular break.

These practical steps won't necessarily make difficult or painful feelings disappear, but they can make it easier to cope with the day-to-day tasks of caring and give you some valuable time to yourself to recharge your batteries.

You are not alone

It is very important to think about how you can organise support for yourself, as well as the person who has had a stroke. It can help to talk through choices and decisions with someone who understands what you are going through.

The Princess Royal Trust Carers Centres are very good sources of local information and support. Phone the CHSS Advice Line for your local Carers Centre.

Chest Heart and Stroke Scotland offers information, advice and support to people who have had strokes and their carers. You can speak to our Advice Line nurses in confidence on 0845 077 6000.

Find out if there is a local Stroke Club or Carers Group whose members can offer a wealth of experience, local knowledge of services, or simply someone to talk to.

What are the chances of a full recovery?

Recovering from a stroke is a gradual process. The time it takes and the degree of recovery varies from person to person. It may take weeks, months, or in a few cases, even years. Some people get completely better. Most people recover enough to be independent in walking, eating and using the toilet, and with support can do many of the things they could do before. Some people improve only a little and need long-term care and support.

Will it happen again?

This is often one of the first questions people ask after a stroke. Research shows that someone who has already had a stroke is at higher risk of having another than someone who has never had a stroke. But statistics only apply to a large group of people. They don't tell you much about the risks for each individual. A lot depends on things that are specific to the person, such as type of stroke, his or her age, and overall state of health.

Reducing the risk of another stroke

Depending on each individual situation a lot can be done to reduce the chance of having another stroke. The doctor may suggest specific treatments, which can help to reduce the risk. There are also steps that you and the person you care for can take on your own (for example, changes in lifestyle such as stopping smoking or losing weight).

Ask for the CHSS booklet called ‘Reducing the risk of stroke’ for more details.

Warning signs of another stroke

One warning sign could be a transient ischaemic attack (TIA), which is also known as a mini-stroke. It is caused by a temporary reduction in the blood supply to the eye or brain. The symptoms are similar to a stroke but wear off within 24 hours – and sometimes in minutes. Temporary blind spots or distortion of vision, difficulty in talking, or numbness, tingling or weakness of a limb or of one side of the face or body are all symptoms of a TIA. If the person you care for experiences any of these he or she should see a doctor quickly. However if you suspect any new symptoms or notice deterioration in the person who has had a stroke, get advice from the doctor straight away. Getting help early may prevent a further stroke or some other associated illness or greatly reduce their effect.

Ask for the CHSS booklet called ‘Understanding Transient Ischaemic Attacks’ for more details.

The doctor’s advice and treatment to reduce the chance of another stroke will partly depend on the cause

COPING AT HOME WITH CARING

Many people feel quite uncertain about how they will cope with caring at home. The social worker is a good person to talk to about this. If you are the main carer, make sure that you know what practical support is available, even if you are not sure at first whether you will need it. Professionals do their best to help, but many services are under resourced. Someone may not realise exactly what support or practical help you need unless you tell them. If you are promised help, write down what is offered, by whom and when. If the promised help does not appear, get in touch with the person concerned to remind them.

Help from social services

If someone needs support services in order to manage at home after a stroke, these are usually arranged through the local council social services department by a social worker. The services available vary from area to area, but include things like help with personal care, special equipment or adaptations to the home, day care, home helps, meals on wheels and respite care.

Arranging an assessment

To work out what services are needed social services will arrange an assessment with the person you care for. In hospital, you may be introduced to a hospital social worker who can help to arrange this. If this does not happen, or if the person you care for was not admitted to hospital, you can contact social services directly to ask for an assessment. (Your local social work department is in the phone book under the name of your local council, and you phone the office nearest you.)

Ask for a carer's assessment

If the person you care for is eligible for an assessment, and you provide a substantial part of their care, you have a right to a separate assessment of your own needs under the Carers (Recognition and Services) Act 1995.

The Carers Act does not give carers the right to services for themselves. But it does mean that 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 for the person needing care.

This could mean, for example, regular respite care is included in the support arranged for the person who has had a stroke, to give you a break. Some social services departments do offer specific support to carers, but what is available varies from area to area.

Getting the most from an assessment

Before the assessment it is worth thinking carefully about what kind of support you both need. You may find it useful to keep a diary for a week to record the daily needs of the person who has had a stroke, and the caring tasks that you do.

Write down your ideas about things that would help the person you care for to become more independent – for example, equipment, changes to the home, or help with transport. Also think about the things that you would both most like to achieve. These might be:

- practical things – for example, improving communication difficulties, help with personal care
- social goals – for example, getting out, meeting new friends
- emotional support – for example, other company for the person you care for or for you, ways you can reduce stress.

Social services should review the situation from time to time to see whether the needs of the person you are caring for have changed. But if your situation changes and the person who has had a stroke needs more or different kinds of help, ask for a review straight away.

Social services must take into account the person's ability to pay for support services

Financial assessment

Social services may charge for support services. Assessment will include questions about personal finances to find out how much, if anything, the person who has had a stroke can afford to pay. Charges for services vary from area to area, but social services must take into account the person's ability to pay. If the charge seems unreasonable, the person needing care has the right to ask social services for a review.

If you have difficulty in getting an assessment for the person needing care, are refused services that you really need, or feel that a charge is unreasonable, contact the social services customer services section. Their job is to help you sort out the problem, or tell you how to ask for a review or make a formal complaint. Before you do this, it is a good idea to get advice from your local Citizens Advice Bureau.

Money and legal matters

Caring for someone who has had a stroke is likely to involve extra expense – for example, paying someone to help with caring, larger heating bills, extra equipment or perhaps alterations to the home. It may also mean a drop in income if you or the person you care for has to give up work. You may both be entitled to financial benefits, which will help you to meet some of these costs. You may be able to get help towards the cost of prescriptions.

There may be other financial and legal arrangements to consider. For example, the person who has had a stroke may need help in managing his or her affairs. If either of you gives up work, it is a good idea to check what help you are entitled to under your pension scheme, or whether you can protect your pension rights.

Benefits and allowances

The benefits system is complex, and changes frequently, so it is a good idea to get advice about what you are entitled to, and how to fill in claim forms. There are different benefits and allowances for people who are ill or disabled, for people who are carers and for people who are on low incomes. People on low incomes may also get housing benefit to help with the cost of rent, help with Council Tax and help with NHS costs such as travel to and from hospital.

Some benefits are taxed; some cancel each other out, some act as passports to other benefits.

Your benefits will be handled by your local Department of Work and Pensions, formerly known as the Benefits Agency.

Independent Advice

Local advice centres such as Citizens Advice Bureau know their way round the benefit system and can give you independent advice if you are trying to work out what you should claim for. Your local council office may also be able to give you details about their local welfare or benefits advice centres that you can visit or phone usually attached to the social work department welfare rights.

Be as positive as possible

Rehabilitation after a stroke is a slow process and it is common for someone who has had a stroke to feel quite low after returning home. The person you care for may need a lot of encouragement from you and other family members. Praise every sign of progress, however small. Try to give constant reassurance that things will get better, especially during the periods when progress seems slow.

Don't be overprotective

It is natural to want to protect the person who has had a stroke, but it is important to get the balance right between helping and encouraging independence. Encourage the person you care for to do as much as he or she is able right from the start. This may be a very gradual process of small steps at a time. It may be time-consuming and frustrating at first, but in the long run it is the best way to help the person you care for relearn skills and regain confidence and independence.

Be conscientious about rehabilitation exercises

People often lose the incentive to continue their rehabilitation exercises after leaving hospital but regular exercise does increase recovery. Practise little and often. After a stroke people tend to tire very easily. Short sessions at regular points in the day are much better than longer sessions less often.

Be patient

It can sometimes seem that the person who has had a stroke is not making any effort, or is even being deliberately awkward. This is not usually the case, but there are a number of reasons why it may seem so.

Stroke causes physical damage to the brain, which can make it difficult to relearn the simplest tasks. It can also cause problems with understanding, memory and communication. It can affect control of balance and movement. It can increase previous problems with the chest, joints or limbs, making movement more difficult even though there is no actual paralysis. These symptoms can make someone seem lazy or stubborn when they are not.

Tiredness after a stroke is common and if the person has done too much one day, they may not be able to so much the next.

Be aware that the person affected by stroke may find being home or out and about quite daunting. This can be because they find too much noise and a lot going on quite disturbing such as at the supermarket, or in crowds. At home it may be difficult to concentrate on reading or communicating if there is other interference such as background noise. Some people find watching television disturbing. Basically you can not assume the same things will still be pleasant that were before.

Build up your social life

Many people who have had strokes feel embarrassed about their weakness or speech difficulties. They may feel self conscious and lacking in confidence. The person you care for 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.

Talk to friends about what has happened. Explain that what the person you care for needs is not sympathy or pretence that nothing has happened, but honest recognition that he or she has been changed by the stroke but is still a complete person who needs friends. Encourage friends to visit, perhaps start with a visit from one person and plan a short return visit to them. Work out ways of gradually rebuilding your social life so that you continue to see friends and go out together right from the start, if you can.

You may need to accept that some friendships may fade away. This may be because they are based on a shared activity that the person you care for can no longer do.

Though hurtful, it is quite common for some friends to avoid contact because they feel embarrassed by the change in the person who has had a stroke. You may need to build up new friendships and social activities with people who share your interests. Stroke clubs and carers groups can be a good starting point.

Set up a daily routine

Aim to build up a daily routine that meets both your needs. This may take time and perseverance at first, but a regular routine will help recovery. Think about the necessary daily tasks that the person you care for can do independently, can begin to relearn or will need help with. Plot the time that will be needed for these. 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.

Encourage the person who has had the stroke to have a regular rest if they get easily tired.

The person who has had a stroke may have a best time of day – use this for the things he or she most wants to do, not for tedious tasks. Encourage the person you care for to continue with hobbies, interests or other regular commitments that are still feasible, and plan time for these.

Try to organise the day so that you have some time to yourself. Ask family members or friends for help with specific tasks, if you need it. People who offer to help usually genuinely want to. But they need you to tell them how.

Rehabilitation

It is important to start rehabilitation as soon as possible. The sooner it starts the more effective it is. For people who are admitted to hospital, rehabilitation begins before they return home. Ask about rehabilitation services if the person who has had a stroke is not admitted to hospital and the GP does not mention it straight away. It will be helpful if you are involved in meetings with therapists at the start so you can learn the exercises along with the person you care for. This will help you understand what is needed and give him or her extra encouragement to do exercises regularly.

Lifting and moving

The physiotherapist, district nurse or occupational therapist can show you how to handle and move the person you care for so as not to cause injury to him or her – or to yourself. If the stroke has resulted in a weak arm, take care never to lift the person you care for by pulling on it. This may hurt or even dislocate the shoulder.

> ***It will be helpful if you can learn the exercises along with the person you care for***

Swallowing

Swallowing involves many different muscles and nerves. If the stroke affects any of these it can cause difficulty with eating and drinking. If not tackled, swallowing difficulties can lead to other problems such as dehydration and constipation (due to lack of fluids) or a chest infection (because food or saliva passes into the windpipe). If the person who has had a stroke has difficulty swallowing, ask the GP to refer him or her to a speech and language therapist, who can diagnose the cause of the difficulties and help prevent other complications.

At mealtimes you can help ensure safer swallowing by sitting the person you care for in an upright position, with the head tilted down and chin slightly tucked in. Use pillows for support if necessary. If in doubt, contact the speech and language therapist

Incontinence

A stroke can lead to a loss of bladder control (urinary incontinence), bowel control (faecal incontinence), or both (double incontinence). This does not necessarily mean that incontinence is permanent. Bladder and bowel control can be affected for many different reasons. For some people it is a matter of time – controls will improve with general recovery. For others, specific help or treatment can be given. With the right help, it is sometimes possible to cure incontinence completely, or to improve it and make it more manageable.

Discuss the problem with your GP or hospital doctor. They can give advice, carry out tests and call on help from your local continence nurse if there is one in your area if necessary. Depending on the cause, it may be possible to improve continence with the help of drugs, bladder training, and exercises to increase mobility, equipment to make it easier to go to the toilet, or remain dry and comfortable, adaptations to toilet facilities, or a combination of these. You may also be able to get financial help with the extra costs of incontinence equipment.

Communicating

If the stroke has affected a person's ability to understand, speak, read or write, it is important to get the problem accurately assessed by a speech and language therapist. The therapist will draw up a plan of treatment to help recover the language that has been lost and explain how to make the most of the communication skills that remain. The daily practice of skills at home, and the involvement and encouragement of relatives and friends can make a big difference to the level of recovery. At Chest Heart and Stroke Scotland we have special groups around the country for those people who have speech and language problems. This is known as the Volunteer Stroke Service. Volunteers and staff are trained to teach supported conversation. For more details telephone us on 0131 225 6963

Falls

Someone who is learning to walk again is likely to fall more easily. Be prepared for this, but don't prevent the person you care for from being active, as this will slow down recovery. Try and make the environment as safe as possible, keeping the floor clear of obstacles and loose mats. Avoid uneven surfaces and encourage the use of sticks or zimmers if they have been provided. If someone has visual problems their safety can be affected and they may need more support.

A physiotherapist can offer advice and guidance on safety issues. Don't let the person tackle stairs alone unless they have been checked to be safe by a physio.

Epilepsy

In a few people, the scar that results from the stroke can irritate the brain and cause epileptic fits, sometimes weeks or months later. If someone has a fit, the most important thing is to clear a space around him or her so that they cannot hurt themselves, and to keep the person's airway clear. Then contact the GP. Most people who experience fits are prescribed medication to control this. CHSS can provide a booklet by Epilepsy Scotland called 'A guide to epilepsy'

Central post stroke pain (CPSP)

A small percentage of people who have strokes develop central post-stroke pain some time afterwards. This is a burning, shooting and throbbing pain that is not eased by painkillers. It can be treated, but some GPs are not well informed about the condition.

COPING WITH EMOTIONAL NEEDS

A stroke can cause psychological as well as physical changes. Common changes are tiredness; loss of concentration or initiative; poor short-term memory; and irritability, anger or frustration.

Depression

If the person you care for becomes locked into anxiety or depression that cannot be shaken off, it is important to get medical help. The earlier that serious depression is diagnosed, the sooner it can be treated. Many people that are depressed feel unable to do anything about it and you may have to encourage them to seek help. If they have communication problems you may have to speak for them about it to the doctor if you feel they have been very low for a while. Common signs of depression are changes in appetite, changes in sleep pattern, loss of interest in self, mood swings, being easily upset or crying a lot, loss of motivation and energy, difficulty concentrating.

Emotional control

Stroke often affects the ability to control emotions. The person you care for may experience intense feelings that he or she is simply unable to control. Excessive weeping or laughter – sometimes at inappropriate times – emotional outbursts, and uncontrolled swearing may also result from stroke damage. These are often as distressing to the person who has had the stroke as they are to others. Reassure the person you care for that these problems are not signs of madness or dementia.

Cognitive effects

Stroke may also affect mental (cognitive) processes such as the ability to make sense of what you see, to judge space or distance, to focus attention, to recognise familiar objects, or to solve problems or organise tasks. The loss of these abilities can in turn cause intense anxiety, fear or depression. Once cognitive problems are correctly diagnosed, it may be possible to do something about them and so reduce the anxiety or depression they cause. Talk to the GP who may refer the person you care for to a clinical psychologist.

Understanding emotional outbursts

The ability to eat, talk, walk, dress, wash and use the toilet without help is central to our self-esteem. Because of this, the person you care for is likely to put a lot of effort into trying to achieve them. You may find that even small failures can trigger intense frustration, despondency or anger.

Try to detach yourself from emotional outbursts. If you can keep calm and help the person you care for to be specific about the problem, you may be able to find ways of overcoming it – for example, by tackling a task or difficulty in much smaller steps, so that it can be built up gradually. People, who are determined, tend to make a better recovery after a stroke. Your praise, encouragement and practical help with rehabilitation can make a real difference to this.

Personality changes

Some people talk about changes in a person's personality after a stroke. In fact, what happens is that a stroke can change an aspect of someone's character. This means that it is often possible to do something about it or get advice on how to cope with it. If the stroke has affected the personality or behaviour of the person you care for in ways that are bewildering or distressing, he or she may need specialist help.

Serious changes may affect your feelings towards the person you care for. It is helpful to keep reminding yourself, and others, that the changes are the result of the stroke and that the person you care for has no control over them. If there are serious difficulties ask your GP for a referral to a psychiatrist, clinical psychologist or psycho-geriatrician – don't simply accept 'personality' problems.

ROLES AND RELATIONSHIPS

A stroke is likely to change the life of the person you care for, and the lives of other family members, in many different ways. The person who has had a stroke may have less control over the small everyday decisions that we all make without thinking – when to have a cup of tea, phone a friend, turn on the TV. 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.

Adapting to caring and nursing roles

Caring for someone who is no longer independent inevitably changes the relationship between you. Carers sometimes feel guilty that they may have done something to cause the stroke, distressed by the effects of stroke on the person they love, overwhelmed by the demands of caring, and, at times, resentful towards the person they care for. The person needing care may feel frustrated, despairing or angry at the loss of control over his or her life, and vent these feelings on you and other family members. It is important to acknowledge these feelings, and recognise that they are normal reactions to stress. Once you acknowledge them, you can start to do something about them. If you are the main carer, looking after yourself is as important as looking after the person you care for.

Sex after stroke illness

Some people are anxious about whether they will be able to continue to have a sex life after a stroke. Some lose interest altogether. A common worry is that sex could trigger another stroke. This is not the case for most people, but someone with high blood pressure who has had a haemorrhage-type stroke should get advice from the doctor.

Ask for the CHSS booklet called ‘Sex after stroke illness’ for more details.

Finding new responsibilities and encouraging independence

It helps to encourage the person who has had a stroke to take on responsibilities within the family right from the start. If the person you care for cannot fulfil his or her former role, finding new roles and responsibilities that are manageable will help to boost confidence and maintain the respect of other family members.

Regaining independence is likely to involve considerable effort, determination and frustration. Sometimes the person who has had a stroke can demand a great deal of time and attention. It may help to decide on firm limits about what you will and will not do, in order to motivate the person you care for and stretch his or her abilities.

Deciding whether to give up work

A stroke can make it difficult or impossible for the person affected to continue working. If it is feasible, it makes sense to delay the decision to stop work altogether until it is clear how far the person is likely to recover. It is sometimes possible to arrange leave of absence, or to move to part-time work, rather than giving up a job entirely. Ask the personnel officer or trade union representative for advice.

For the carer, it may seem a sensible decision to stop work in order to make more time for caring. Think through the implications carefully. 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 other alternatives, such as reducing the hours you work, if possible, or perhaps finding a part-time job nearer home.

Think through the implications of giving up your job carefully

Because of the value we attach to work in our society, giving up a job can seriously affect our own sense of worth and self-esteem. If either of you does decide to stop working, it is a good idea to find other regular activities to get involved in – either separately or together – which will take you out of the home and bring you into contact with the other people.

Younger adults

Although stroke is more common in older people it can affect people of all ages. Younger adults who have a stroke may have considerable financial and family responsibilities. While diseases of old age do not complicate recovery in younger people, the idea of disability and the loss of hopes and aspirations may be very hard to come to terms with.

The partner and children of the person who has had a stroke have to cope with a new set of practical and emotional pressures, and adjusting to these often takes time. Children may have to take on new roles and responsibilities, and get

used to both parents having less time to spend on their needs. It is important to talk to children frankly about what has happened and about how it will change family life.

If you would like further information about stroke and younger adults telephone our Advice Line Nurses. Different Strokes is an organisation set up for young stroke survivors. You may wish to telephone them on 01908 236 033.

LOOKING AFTER 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 run the risk of becoming so stressed or exhausted that you are no longer able to care for the person who has had a stroke.

Looking after your own health

Think about what you can do to look after your health. Common problems are back strain, from lifting or moving the person needing care, tiredness and stress. Stress can cause sleeplessness, loss of appetite, intense anxiety and depression. Many carers find themselves smoking and drinking more, to relieve some of the stresses of caring. This may seem to help in the short term, but in the long term cigarettes and excessive alcohol will damage your health. If you would like to cut down smoking or drinking, talk to your GP.

A district nurse or physiotherapist can teach you how to move or lift someone so that you don't strain your back. They may also be able to show you relaxation techniques that will help symptoms of tiredness and stress. Most big bookshops offer a range of books and tapes on advice and relaxation techniques to deal with stress. If you manage to organise a gentle exercise routine, which takes you out of the house for half an hour, several times a week, this can increase your energy levels and help you feel more positive.

Getting a break from caring

Many carers say that getting a regular break – and using it to the full allowing them to let off steam or enjoy themselves – is invaluable. Research by Carers National Association shows that giving carers a break is one of the most effective ways to help them carry on.

'Respite care' is the term used for services designed to give the main carer a break. Respite care can take the form of:

- care in the home from a trained care assistant or volunteer, for a few hours a week
- care outside the home, for example, at a day centre, lunch club or social club
- longer breaks – from a few days to a couple of weeks – in a residential or nursing home or possibly NHS hospital.

You can also get specialist help with arranging holidays for people with disabilities.

Ask at Chest Heart and Stroke Scotland for our holiday factsheet.

You can also apply to Chest Heart and Stroke Scotland for a welfare grant toward the cost of a holiday for you and you partner – telephone 0131 225 6963.

The services available to provide respite care vary widely from area to area. Ask social services about what is available in your area, from voluntary organisations as well as the NHS. Some respite care services may charge, or ask you to contribute towards the costs.

Support from other carers

You may at first not think of yourself as a ‘carer’. Every carer is an individual, and each caring situation is unique. But, you are likely to find that most people who do not have experience of caring for another adult have no idea what it involves.

Carers do have a lot in common, and it can be very helpful to meet and talk to other people who understand exactly what you’re going through. It is worth finding out if there is a carers group or stroke club in your area. Attending a stroke club gives you the opportunity to meet other carers to discuss common problems and to provide mutual support, for example.

If you don’t like the idea of joining a group and many people don’t, it is still worth getting in touch with the group organiser. They may offer to keep in touch with you by phone, or to put you in touch with a carer in your area. To find out if there is a group in your area telephone Chest Heart and Stroke Scotland on 0131 225 6963.

WORK TOGETHER TOWARDS A POSITIVE FUTURE

When looking for new interests and things to give you a break look as well for things you can both enjoy. Recognise that the stroke will change your lives but that this need not prevent you from having new hopes and goals for the future. What matters is for you both to decide what you want to do most in life. This is likely to be different for both of you. Plan what practical steps you can each take to work towards your goals, given your limitations. Try starting with a simple target that's easy to achieve within a few days. See how you feel when you've achieved it. Even when you are feeling low you will find that you can change things by gradually building up from small successes to bigger ones.

Phone/Textphone the Chest, Heart and Stroke Advice Line for confidential, independent advice from one of our nurses.

The line is open

Monday - Friday
9.30 - 12.30 and 1.30 - 4.00

0845 077 6000

Charged at local call rate.

Out of hours answering machine.

Email: adviceline@chss.org.uk

Fax: 0131 220 6313

STROKE PUBLICATIONS

Booklets

SS1	Stroke a guide to your recovery
SS2	Stroke: a carers guide
SS3	Reducing the risk of stroke
SS4	I've had a stroke: Essential information on admission to hospital
SS5	Understanding TIA's
SS6	Sex after stroke illness
H4	Living with High Blood Pressure

Video - Stroke Matters: £30.00

Resource pack comprising two videos and two booklets
(This video can be hired as well as bought.)
Booklets are available separately: Making sense of stroke and Facing the future.

Factsheets

F1	TB: Information about tuberculosis
F2	Salt
F3	Cholesterol
F4	Warfarin
F5	Helping someone with language problems
F6	Holidays
F7	Insurance companies
F8	Suggested book list
F9	Driving after a stroke
F10	10 common questions asked after a stroke
F11	Mouthcare after a stroke
F12	BCG - Protection against tuberculosis
F13	Air travel for people affected by chest, heart and stroke illness
F14	Eye problems after stroke
F15	Memory problems after stroke

A full publication list is available from Head Office.

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We need £3 million a year to fulfil our commitment to improving lives for Scottish people. We need your help and your money to help others. You can help by volunteering your time as a fundraiser, VSS volunteer or support your local Regional office. You can send a donation, remember us in your Will, take out a Deed of Covenant or organise a fundraising event.

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If you would like to speak to one of our Advice Line nurses, in confidence, phone the Chest, Heart and Stroke Scotland Advice Line

Monday – Friday
9.30am - 12.30 and 1.30pm - 4.00pm

0845 077 6000

Email: adviceline@chss.org.uk
Textphone available

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March 2004