STROKE
A carer’s guide

STROKE SERIES SS2

NO LIFE HALF LIVED
The information contained in this booklet is based on guidelines and practice and is correct at time of printing. The content has undergone peer, patient and expert review.
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WHO IS A CARER?

You may not think of yourself as a ‘carer’ but 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. Carers, whatever 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.

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.

See the CHSS booklet: ‘Stroke: a guide to your recovery.’ for more information.

There is a full list of booklets and factsheets inside the back cover of the booklet.

www.stroke4carers.org
An online resource for unpaid carers, family and friends of anyone who has been affected by stroke illness. Includes practical tips, film clips, interactive graphics and quizzes.
There is a lot to take in in the first few weeks after a stroke. 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.

**Emotional effects on the family**
A stroke can be a shock to your whole family / social circle. You, and other close family members / friends may feel a deep sense of loss, because a stroke can change the person you knew and loved. You may go through feelings of loss and grief for the way that your life and that of the person you care for has changed.

Caring can be 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 feelings are the result of doing a very demanding job.

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

**Simple steps**
At the beginning many people cope by getting by one day at a time. However, this is not a basis for long-term care.
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Simple steps

At the beginning many people cope by getting by one day at a time. However, 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. They can also help to 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.

Carers centres can be very good sources of local information and support. Phone the CHSS Advice Line Nurses, free from landlines and mobiles, on 0808 801 0899 for details of your local carers centre. You could also search online or see your local phone book.

CHSS offers information, advice and support to people who have had strokes and their carers. You can speak to our Advice Line Nurses in confidence. Our Advice Line Nurses can also help you find out if there is a local stroke or carer support 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 stroke. Remember that everyone will have their own individual risk factors. A lot depends on things that are specific to the person, such as type of stroke, age, and overall state of health.

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. However, controlling individual risk factors will reduce the risk of having another stroke. This is known as secondary prevention. The doctor may suggest specific treatments to do this. There are also steps that you, and the person you care for, can take on your own (for example, stopping smoking or losing weight).

See the CHSS booklet ‘Reducing the risk of stroke’ for more information.
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See the CHSS booklet 'Reducing the risk of stroke' for more information.

**Warning signs of another stroke**
If you suspect any new symptoms in the person who has had a stroke seek medical help straight away. Numbness, tingling, or weakness of a limb or of one side of the body, difficulty in talking, temporary blind spots or distortion of vision, and sudden loss of balance are all symptoms of stroke.

It is important to remember that fatigue can cause temporary worsening of any problems the person you care for has had as a result of their stroke. For example many people with communication difficulties will find their speech is worse in the evening when they are tired than it is in the morning when they are rested after a night’s sleep.
It is quite normal to feel unsure about how you will cope with caring at home; it can often help to chat things through with a social worker or other health professional. 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 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**

Each local council has a social work department (sometimes called social care or social services) which has a major responsibility for organising / coordinating community care services. If someone needs support services in order to manage at home after a stroke, these are usually arranged through this department. 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 care assistants, meal service and respite care. A care package to help with personal care tasks and meal preparation may be arranged before discharge but can also be arranged once the person gets home.
Everyone’s needs are unique: no two people will require exactly the same amount, or type, of support. In order to ensure that you get the support that is right for you, the way that some services are provided in Scotland is changing. Local councils now have a legal duty to involve you in decisions about your support.

**Self-directed support**

The Social Care (Self-directed Support) (Scotland) Act 2013 came into force in 2014. This Act gives the person you care for a range of options for how their (social) care is delivered.

Self-directed support aims to give someone choice and control over their care: they can decide how much ongoing control and responsibility they want over their own support arrangements. Some people will choose to have lots of control over their care and support and some will leave most of the
decisions / work to their local council. Other people may do a bit of both. The important thing is that someone has a choice.

Self-directed support is a new concept to most people and may seem a bit daunting at first. However, there is lots of information and support available to help you understand the process.

See the ‘Useful addresses and websites’ section at the end of this booklet for more information.

**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 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 you are a carer then you are entitled to a carer’s assessment. This means that you can have your needs assessed in relation to the person you are caring for – even if you don’t live with him / her.

The assessment is to work out with you:
- how much care you are providing and whether you can continue to do so.
- what support you need in order to continue caring and stay healthy.
Your assessment helps your local council decide whether you are eligible for support with your caring role.

This could mean, for example, regular respite care is included in the support arranged for the person who has had a stroke in order 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. Also think about the things that you would both most like to achieve.
These might be:

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

Social services should review your 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.

**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 to 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, e.g. 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.

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. Always seek independent advice in relation to these matters.
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 ‘means tested,’ i.e. your eligibility will depend on what income and savings you and your spouse / partner have.

Your benefits will be handled by the Department of Work and Pensions, formerly known as the Benefits Agency. The gov.uk website has lots of useful information about financial support and benefits including an online benefits advisor calculator.

Independent advice

Local advice centres such as Citizens Advice Bureaux or Carers Centres 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. Your Stroke Nurse will also know what is available locally.

See the CHSS factsheet ‘F41 Financial support’ for more information.
BECOMING A CARER

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.

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. However, 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 actually trying their best.

Tiredness after a stroke is common and if the person has done too much one day, they may not be able to do 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, e.g. being 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 cannot assume the things which the person enjoyed before will be the same after the stroke.
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Build up your social life

Many people who have had a stroke feel embarrassed about their weakness or speech difficulty. 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 the person you care for does not need sympathy or pretence that nothing has happened. Instead, they need 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; it might help to 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.

You may need to build up new friendships and social activities with people who share your interests. Stroke and carer support 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 regular rest breaks as they will 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.
In Scotland patients having a stroke should be admitted to hospital or be assessed in hospital stroke clinics.

**Rehabilitation**

It is important that rehabilitation is started as soon as possible. It can be helpful if the nurses and therapists involve you and teach you how you can best help and encourage the person you care for.

**Lifting and moving**

The physiotherapist, 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.

See the CHSS poster F16 ‘Positioning for people affected by stroke’ for more information.

**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). Swallowing difficulties will be assessed by the speech and language therapist, who will give guidance regarding all aspects of safe swallowing and feeding.

See the CHSS factsheet F29 ‘Swallowing problems after stroke’ for more information.
Continence problems
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 – control will improve with general recovery. For others, specific help or treatment can be given.

Discuss the problem with your hospital doctor or GP. They will carry out tests, give advice, and refer you if necessary to the district nurse or the specialist continence nurse, if there is one of those in your area. You may be able to get financial help with the extra costs of incontinence equipment.

See the CHSS factsheet F12 ‘Continence problems after stroke’ for more information.

Communicating
If the stroke has affected the person’s ability to understand, speak, read or write, it is important that these problems are accurately assessed by a speech and language therapist. The therapist will draw up an individual treatment plan aimed at improving these problems, and will explain how to make the most of any 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. CHSS has Communication Support Groups around Scotland for people with speech
and language problems after stroke. Volunteers and staff are trained to use supported conversation with the members. For more details telephone us on 0808 801 0899.

See the CHSS factsheet F5 ‘Helping someone with communication problems’ for more information.

**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 walking frames if they have been provided. If someone has visual problems their safety can be affected and they may need more support.

A physiotherapist or occupational therapist can offer advice and guidance on safety issues. Don’t let the person tackle stairs alone unless they have been assessed to be safe.
**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 for the first time it is important to seek urgent medical aid. Your GP can also give advice regarding first aid in the event of any subsequent fits occurring. Most people who experience fits are given medication to help control this.

**Central post-stroke pain**

A small percentage of people who have strokes develop central post-stroke pain some time afterwards. This is a burning, shooting or throbbing nerve pain that is not eased by taking commonly used painkiller. Referral to pain clinic is often necessary.

*See the CHSS factsheet F33 ‘Understanding central post stroke pain’ for more information.*
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.

**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 simply another effect of their stroke.

**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.

**Cognitive and perceptual problems**

Stroke may affect cognition, which refers to problems with memory, problem solving, planning tasks and focusing the attention. It may also affect perception which can lead to problems in areas such as judging space and distance, recognising objects, sequencing tasks in the right order, or neglecting one side, or part, of the body. Once these problems are correctly assessed by the Occupational Therapist a plan will be drawn up to help to aid treatment.
Personality changes
Some people talk about changes in a person’s personality after a stroke. In fact, what may be happening is that the stroke changes aspects of someone’s character. If you are finding any of these changes difficult to understand, or cope with, speak to your doctor, therapist, or stroke nurse for help and advice.

See the CHSS booklets ‘Coming to terms with stroke’ and ‘Thinking and behaviour issues after stroke’ for more information.

Depression
It is usual to feel low in mood at times after having had a stroke. Sometimes, however, prolonged and more frequent low mood can lead to depression if left untreated. Common signs of depression are: changes in appetite; changes in sleep pattern; loss of interest in appearance; mood swings; loss of
motivation and energy; difficulty concentrating; and being easily upset or crying a lot.

It is important that depression is recognised so that treatment can be given. Treatment is usually very effective. Speak to your doctor or stroke nurse if you are worried that the person you care for is becoming depressed.

See the CHSS factsheet F37 ‘Coping with low mood/depression’ for more information.
A stroke is likely to change the life of the person you care for, and the lives of other close family members / friends, 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, e.g. 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 close family members / friends. 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 their doctor.

See the CHSS booklet ‘Sex after stroke illness’ for more information.

**Encouraging independence**

If you are not sure what activities the person you care for is capable of speak to your stroke nurse or therapists about this. It can demoralise the person if they are given a task that is inappropriate or beyond their level of recovery. Breaking tasks down into more manageable steps can help until the person improves and gains confidence to move forward with their rehabilitation. Try new things when they are ready. Support and supervise rather than take over. Once you are both confident you can let the
person do the task independently. This will give them a great sense of achievement.

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. Speak to your employer or HR department, if there is one.

For you, the carer, it may seem a sensible decision to stop work in order to make more time for caring. However, 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 your 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.

Because of the value we attach to work in your society, giving up a job can seriously affect your 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 your home and bring you into contact with 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. In addition, 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.

See the CHSS booklet ‘Stroke in younger people’ for more information.
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 include: back strain (from lifting or moving the person needing care), tiredness and stress. Stress can cause sleeplessness, loss of appetite, intense anxiety and depression. Some carers who already smoke or take alcohol may find themselves smoking and drinking more to relieve stress. This may seem to help in the short term, but in the long term cigarettes and excessive alcohol will damage your own health. If you are concerned about your health or, for example, you would like to cut down smoking or drinking, talk to your GP.

An occupational therapist may be able to show you relaxation techniques that will help symptoms of tiredness and stress. You can buy books / CDs on relaxation techniques – try a local bookstore or searching online. You can also get some good apps (for smartphones) which offer practical advice and tips on dealing 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.

See the CHSS factsheet F23 ‘Living with stress and anxiety’ for more information.
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 UK 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 volunteer or befriender, 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 private residential or nursing home or possibly NHS hospital

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, such as Shared Care, as well as the NHS. Some respite care services may charge, or ask you to contribute towards the costs.

If you feel like going for a well-deserved holiday together there are specialist organisations that can help you with arrangements. Help might come in the form of transport, providing practical care or finding accessible accommodation.
You can also apply to CHSS for a personal support grant towards the cost of a holiday for you and your partner – phone our head office for details on 0131 225 6963.

See the CHSS factsheet ‘Holiday information’ for more information.

**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 in your area. Attending such a group gives you the opportunity to meet other carers to discuss common problems and to provide mutual support.

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 the CHSS Advice Line Nurses on freephone 0808 801 0899.
WORK TOGETHER TOWARDS A POSITIVE FUTURE

When looking for new interests and things to give you a break, try to also look for things you can both enjoy. Recognise that the stroke may change your lives. However, this does not have to 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. 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.
USEFUL ADDRESSES AND WEBSITES

**Befriending Networks**
63-65 Shandwick Place, Edinburgh EH2 4SD
Tel: 0131 261 8799
Email: info@befriending.co.uk
Website: www.befriending.co.uk

*Befriending Networks has a directory of befriending services throughout Scotland.*

**Carers Scotland**
The Cottage, 21 Pearce Street, Glasgow G51 3UT
Tel: 0141 445 3070
Helpline: 0808 808 7777 (Mon-Fri 10-4pm)
Email: advice@carersuk.org
Website: www.carerscotland.org

*Carers Scotland (part of Carers UK) offers information to carers throughout Scotland as well as details of local support.*

**Carers Trust Scotland**
Skypark 3, 12-14 Elliot Place, Glasgow G3 8EP
Tel: 0300 123 2008
Email: scotland@carers.org
Website: www.carers.org/scotland

*Carers Trust Scotland (formerly The Princess Royal Trust for Carers) provides comprehensive carers’ support services throughout the UK including independently run carers’ centres.*

**Shared Care Scotland**
Dunfermline Business Centre, Izatt Avenue, Dunfermline, Fife KY11 3BZ
Tel: 01383 622462
Email: office@sharedcarescotland.com
Website: www.sharedcarescotland.com

*Shared Care has a database of respite services throughout Scotland. They also have information about holiday provision, befriending schemes and sitting services.*

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**USEFUL WEBSITES**

- [www.direct.gov.uk](http://www.direct.gov.uk) – UK government website which provides a single point of access to information and practical advice about public services. It has information about financial benefits as well as information for disabled people and carers. (NB Some policies/services may be different in Scotland.)
- [www.adviceguide.org.uk/scotland](http://www.adviceguide.org.uk/scotland) – Online advice and information from Citizens Advice.
- [www.selfdirectedsupportscotland.org.uk](http://www.selfdirectedsupportscotland.org.uk) – Scottish Government’s Self-Directed Support (SDS) website. This is a one-stop-shop for information about Self-Directed Support for people who use social care services and health and social care professionals.
- [www.stroke4carers.org](http://www.stroke4carers.org) – An online resource for anyone caring for someone who has been affected by stroke illness.
Shared Care Scotland
Dunfermline Business Centre, Izatt Avenue, Dunfermline, Fife KY11 3BZ
Tel: 01383 622462
Email: office@sharedcarescotland.com
Website: www.sharedcarescotland.com

Shared Care has a database of respite services throughout Scotland. They also have information about holiday provision, befriending schemes and sitting services.

www.direct.gov.uk
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www.adviceguide.org.uk/scotland
Online advice and information from Citizens Advice.

www.selfdirectedsupportscotland.org.uk
Scottish Government’s Self-Directed Support (SDS) website. This is a one-stop-shop for information about Self-Directed Support for people who use social care services and health and social care professionals.

www.stroke4carers.org
An online resource for anyone caring for someone who has been affected by stroke illness.
We hope this information has been useful to you. Our publications are available free to anyone in Scotland who needs them. To view, download or order any resources, visit www.chss.org.uk/publications. If you’d like more information about our publications, please contact our Health Information team: www.chss.org.uk/healthinformation@chss.org.uk. 0131 225 6963. Rosebery House, 9 Haymarket Terrace, Edinburgh EH12 5EZ.

Please note: Our publications are currently being reviewed and updated. Some of the publications referred to in this booklet may no longer be available. For a complete list of our current publications, please visit www.chss.org.uk/publications.

For confidential help, support and advice, call our specialist nurses or visit www.chss.org.uk.

Chest Heart & Stroke Scotland (CHSS) is a wholly Scottish charity. Scottish Charity Number SC018761.
OUR PUBLICATIONS

We hope this information has been useful to you.

Our publications are available free to anyone in Scotland who needs them.

To view, download or order any resources, visit www.chss.org.uk/publications

If you’d like more information about our publications, please contact our Health Information team:

www.chss.org.uk

healthinformation@chss.org.uk

0131 225 6963

Rosebery House,  
9 Haymarket Terrace,  
Edinburgh EH12 5EZ

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Chest Heart & Stroke Scotland is a Scottish charity. Our ambition is to make sure that there is no life half lived in Scotland.

After a diagnosis of a chest or heart condition or a stroke, many people experience fear and isolation and struggle with the impact on their lives. Chest Heart & Stroke Scotland won’t stand for that. The care and support we deliver every day ensures everyone can live the life they want to.

CONTACT US

For confidential advice, support and information call the CHSS Advice Line nurses on Freephone 0808 801 0899 or email adviceline@chss.org.uk

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Chest Heart & Stroke Scotland
Rosebery House, 9 Haymarket Terrace, Edinburgh EH12 5EZ
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