

Chest
Heart &
Stroke
Scotland



Relationships and sex after **STROKE**

STROKE SERIES SS6



NO LIFE HALF LIVED



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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.

RELATIONSHIPS AND SEX AFTER STROKE

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INTRODUCTION

This booklet is for people who have had a stroke and are experiencing changes in their close relationships as a result. It looks at some of the ways that stroke can affect your relationships with family and friends and also how it might affect your physical relationship with your partner. It also explains where you can find further help and support.

A stroke doesn't just affect you but everyone around you too. It can cause changes in emotions and behaviour as well as physical changes that can be challenging to deal with, but there are many things you can do to help you cope with the impact of your stroke on you and those closest to you.

Further information



Throughout the booklet, you will be referred to other CHSS booklets and factsheets for further information. These can be downloaded by visiting the CHSS website **www.chss.org.uk**. Paper copies can be ordered using the order form at the back of this booklet, by emailing **publications@chss.org.uk**, or by calling the Advice Line nurses on **0808 801 0899**.

CHANGES IN RELATIONSHIPS AFTER STROKE

What emotional and physical changes might I experience that could affect my relationships?

Coming to terms with what has happened to you can take time. Everyone's rate of recovery is different and how you feel about yourself and others varies from person to person.

Having a stroke can affect people in many different ways.

- You might feel uncomfortable having to depend on other people or feel that you have lost your independence and / or confidence.
- Your stroke may have damaged parts of the brain that control emotions and this can make things even more challenging for you.
- You may also be dealing with physical changes as a result of your stroke including fatigue, pain, paralysis, muscle stiffness or problems with your vision or speech.

All of these changes, whether physical or emotional, can have a huge impact on your daily life, intimacy with your partner and how you interact with your friends and family. They can put an enormous strain on relationships. However, there are things that you and your loved ones and friends can do to maintain close healthy relationships.

Acknowledging and talking about your worries and the changes that you have experienced since your stroke is essential. It is important to remember that you are not on your own. There are many sources of support to help you adjust to life after stroke. These include support from a dedicated health professional such as a stroke nurse, local support groups, counselling services or helplines such as the CHSS Advice Line nurses.

Emotional support from family and friends can make a huge difference to your recovery. Involving them in your care and rehabilitation can help fight feelings of isolation and can help to increase your motivation to achieve your long-term goals as you continue to recover.



See the CHSS booklet *Coming to terms with stroke* for more information on dealing with your emotions after a stroke.

How might my stroke affect my relationships with my family and friends?

Your stroke may have caused worry and uncertainty for those closest to you. As you continue your recovery, your family and friends will also have to come to terms with how things have changed. They may be struggling to understand how you are feeling and they may not understand how tired you get or that you can't get out as much as you did before.

Your roles within the family may have changed because of your stroke. Members of the family might have to take on some of the things you used to do. For example, they may need to become carer, breadwinner, cook, cleaner or take on childcare. You might feel like you have become a burden to those around you and feel frustrated that you can't do all the things you used to do before. This might lead you to withdraw from family life or friendships or become more irritable with those around you.

If you are in a relationship, your partner might have to change their life to fit with the new situation you are both dealing with. They may have to stop some of their social or leisure activities or have less time for things they enjoy. As a result, they could feel resentment.

Children may also have to take on new roles and responsibilities. They may need to get used to the fact that both parents have less time to spend on their needs. They may also have to give up some of their social and leisure activities. Some children think that what has happened is somehow their fault, or they are worried that you will have another stroke. It is important to talk to children frankly about what has happened and why and how family life may be affected.



CHSS has a series of children's resources aimed at helping children (and grandchildren) come to terms with what has happened to a parent or grandparent after a stroke. These include:

- When my Mum / Dad / Grandad / Gran was ill: ring-bound book with fold-out pages and activities for younger children.



- When my Mum / Dad was ill: A4 comic style for children of reading age.
- Jo's story: A4 magazine article style for older children.



Adult children may also find it difficult as they may feel conflict between helping to look after you and looking after their own family.

Friendships might change because people feel awkward or stay away because they don't know what to do. They may find it more difficult to communicate with you if you have aphasia because of your stroke. CHSS has a factsheet that gives people tips and information about communication after stroke – your family and friends might find this helpful; you could even go through it together.



See the CHSS factsheet *Helping with communication after a stroke* for more information.

It may also be that you are not able to do some of the things that you did with your friends before. You may not be able to get about, or you might just not feel like socialising.

Even if you can't do the things you could do before your stroke, there will still be activities that you can enjoy and do with your family and friends. It is important to focus on what you can do rather than what you can't do. For example, if you enjoyed walking before, but are now in a wheelchair, you can find paths and routes that are wheelchair friendly.

If you can't get out to see people, ask them to come and see you, or even speak to them on the telephone. Even if you don't feel like it, try to keep in touch with your friends. Spending time with friends and family is an important part of moving forward with your recovery.



For more information including tips and advice on how to handle your emotions and changing roles after a stroke visit www.selfhelp4stroke.org

INTIMATE RELATIONSHIPS

How might my stroke affect my relationship with my partner?

Changes after your stroke can affect your relationship with your partner.

It may be that the roles in your relationship will have changed and this can take time to get used to. Your partner may have had to take over as the main carer for the family or as financial provider and this can be difficult to adjust to. Also your partner may have become a carer for you. This can impact on the way you see each other and how you feel about each other. This is more common when your partner's assistance is needed with personal care. If you feel that your appearance has been affected then you are likely to feel less attractive and confident as a result.

You and your partner may have unspoken fears and may avoid intimate encounters as a result of your fears. Some people have difficulty controlling their emotions and moods after a stroke. You may feel angry or irritable and if you have problems with communication this can also lead to tension and feelings of frustration. It can be difficult to talk about how you feel but if you don't, tension and resentment can build up between you. Your partner may need some time to come to terms with a change in roles too. If they have to do more, they might feel tired and irritable as a result.

All these things can mean that coping with the impact of stroke can be difficult for both of you. The most important thing is to keep communicating and take the time to re-establish the relationship. Be open, honest and aware of each other's needs as much as possible.

While you might find that your relationship is put under a lot of strain because of your stroke, some people find that their relationship becomes stronger after a stroke.

If you have communication problems, a speech and language therapist will be able to help you and your partner find ways to communicate your feelings to each other. Another option that can help some couples is counselling as it can provide a safe, comfortable space for you to address any issues together. Your stroke nurse or doctor may be able to recommend a counselling service. Other organisations such as Relate or Relationships Scotland can also help. Relationship therapists also work with individuals and can help you if you think you may have relationship difficulties in the future.

Confidential help lines such as the CHSS Advice Line can also help you or your partner individually.



Call the CHSS Advice Line on
0808 801 0899 (free from landlines
and mobiles) from 9.30am to 4pm
Monday to Friday.

It may also help you or your partner to talk to others who have been through a similar experience and there may be stroke groups near where you live.



To find out about a stroke group near you,
see the CHSS website
www.chss.org.uk/community-stroke-services



How could my stroke affect my sex life?

Many people report a loss of intimacy with their partner after a stroke. However, with good communication and a few practical adjustments there is no reason why you cannot have an active and fulfilled sex life after your stroke.

Intimacy and sex is a normal part of life. If you experience any difficulty in your sex life as a result of your stroke, speak to someone such as your doctor or stroke nurse, as help is available.

If you are in a relationship, delaying intimacy will only increase the anxiety surrounding sex. You will need to find a way to communicate with each other in order to overcome your concerns.

It may be that you have less time for intimacy due to visits from carers, health care professionals, family and friends, and you feel worried about being interrupted. Perhaps you feel you have lost your independence or it might be that one of you would like to have sex but the other doesn't. You may find that your libido (sex drive) is lessened due to:

- Tiredness
- Anxiety
- Depression
- Pain
- Doubts about self-image and worries about the future

Over time this can make things tense between you.

A very common worry for many people who have had a stroke is that having sex will bring on another stroke. However, it is highly unlikely that it will and there is no reason why you cannot begin to have sex if you feel ready to do so. It is normal for your heart to beat faster, your blood pressure to rise and for you to breathe faster during sex.

If you are unsure or worried speak to a healthcare professional you feel comfortable with. They will be used to talking about such personal matters even if you are not. You may also find it helpful to talk to someone who specialises in sex and relationships such as a counsellor or sex therapist. Your doctor can refer you to a specialist health professional if needed.

If you are not in a relationship, you may find it more difficult to resume your sex life than before, so take your time to recover and rebuild your confidence.

A small minority of people might actually find that they have an increased libido after a stroke. This may be due to an improvement in your general feeling of wellbeing as you recover both physically and emotionally, as well as an improved relationship with your partner. Very rarely a stroke can cause a disorder called hypersexuality, which can be related to the area of the brain damaged by your stroke. This is described as an abnormal, increased sexual desire. This can be very distressing for you and your family so if this is a concern, speak to your doctor or stroke nurse.

There is no doubt that issues around sex can be difficult to talk about but there's almost always something that can be done. Keeping an open mind, being able to discuss any issues and giving yourself time to adjust can help toward getting your sex life back on track. If you have any medical concerns before resuming your sexual relationship consult your doctor or stroke nurse.

What physical changes might affect my sex life?

There may be physical changes that will make it difficult for you to resume your sex life after a stroke. As a result, you and your partner may want to look at making some changes.

Feeling tired is very common after stroke and this can mean that you feel too tired for the things you used to enjoy, including sex. Some stroke survivors have a strenuous rehabilitation schedule that involves relearning daily tasks and this can leave little energy for sex. It is important not to rush anything and to take your time to recover. It may help to try having sex at times that you feel most full of energy, such as in the morning.

Physically, stroke can affect you in different ways and some changes may make sex more difficult or uncomfortable. For example:

- Muscle weakness or stiffness can restrict how you move or how you position yourself during sex.
- Pain after stroke or lack of sensation can make sex more uncomfortable.
- Bladder and bowel problems can cause embarrassment and may mean that you want to avoid sex.

Stroke can also affect men and women in different ways. For example, women may find that sexual arousal takes longer after your stroke. There may be a loss of sensation or a degree of vaginal dryness, which may hinder sexual activity.

Men are more likely to be concerned if they find they are unable to achieve or sustain an erection. This can happen after a stroke for many reasons but it is also common after any serious illness. Worrying about failing to have an erection can make things worse. The side effects of some medicines such as antidepressants and some medicines that lower your blood pressure can also cause erection problems. Talk to your doctor as your medication can be reviewed and, if needed, you may be referred to a specialist.

There may be several things that your doctor can recommend, for example:

- A change in medication if side effects are affecting your sex life
- Medicines such as sildenafil (Viagra®), which can help you to achieve an erection
- Referral to a specialist

Do not be tempted to treat yourself with medicines such as sildenafil (Viagra®) as they may not be suitable for you, for example if you have heart disease or are taking blood pressure medication.



What can I do to improve my physical relationship with my partner?

Every relationship will be different but things you might want to think about to improve your sex life with your partner include:

- Spend time together and try to plan for sexual activity in advance, just as you would plan for any other activity. This may not seem very romantic at first but it can help to make sex more comfortable and enjoyable.
- Choose a time when both of you are feeling rested and relaxed and when you won't be interrupted so that you can feel comfortable that your privacy is guaranteed.
- Pay attention to your personal appearance as this will help make you feel more attractive and better about yourself.
- Avoid a heavy meal or excessive alcohol beforehand as this will cause tiredness or drowsiness. Alcohol can have an effect on the ability to achieve or maintain an erection.
- If your stroke has affected your movement or sensation, explore different positions which might suit you both better. Find a comfortable position that supports you and conserves your energy. There are also products or cushions to support affected limbs.
- Having a urinary catheter need not prevent you from having penetrative sex. Women can tape the tube out of the way and men can wear a condom with the tube folded back over the penis. There are also other options available so discuss these with your stroke team, health professional or doctor.

- Talk to your partner and share your feelings. Discuss changes you need to make or any problems you are experiencing. Ways around difficulties can often be found.

There are also other ways of expressing your feelings for someone and achieving sexual fulfilment even if you feel unable to manage penetrative sex. Don't underestimate the importance of other forms of physical contact such as kissing, cuddling and massage. Touching can become an important way for you and your partner to express how you feel about each other.

If you would like to speak to someone confidentially about your relationships and sex life following a stroke, you can call the CHSS Advice Line nurses on 0808 801 0899.

Can I still have children?

A stroke is unlikely to affect having a future healthy pregnancy and baby. If you are planning to have children, discuss this with a health professional.

What about contraception?

There is a small increased risk of stroke associated with using contraceptives that contain hormones (such as the combined contraceptive pill). You may need to use alternative means of contraception so talk to your GP or family planning clinic about what is the best method for you.

HELP AND SUPPORT FROM CHSS

CHSS Stroke Nurse & Therapist Service

In several areas of Scotland, people with a new diagnosis of stroke or TIA (transient ischaemic attack, or 'mini stroke') who are discharged home are supported by the CHSS stroke nurses or therapists. This can be for up to a year after discharge from hospital. They help people adjust to life at home after a stroke by giving advice, information and support, and by encouraging and supporting patients to self-manage their condition.

Advice Line

Call the award-winning CHSS Advice Line on 0808 801 0899. Staffed by nurses, the Advice Line is open Monday to Friday 9.30am-4.00pm and provides confidential, independent advice on all aspects of stroke illness.

Health Information

A full range of booklets and factsheets is available via the CHSS website (www.chss.org.uk), by emailing publications@chss.org.uk or by calling 0131 225 6963. These range from resources to help children understand what is happening when a parent or grandparent has had a stroke to resources for people with communication difficulties such as aphasia.

Selfhelp4stroke

This is a self-management website for anyone who has had a stroke with information in video, audio and interactive formats. It aims to offer support and helpful techniques from other people who have had a stroke. Find out more at www.selfhelp4stroke.org

Stroke4carers

This is an online resource providing advice, support and information for informal carers. Find out more at www.stroke4carers.org

Support groups

It can be helpful to hear how other people who have had a stroke cope. CHSS has a number of support groups across Scotland where you can meet other people who have been through a similar experience. For more information, or to find out if there is a group near you, contact the CHSS Advice Line nurses (0808 801 0899).

USEFUL ADDRESSES AND WEBSITES

Chest Heart & Stroke Scotland

Rosebery House, 9 Haymarket Terrace

Edinburgh EH12 5EZ

Tel: 0131 225 6963

Advice Line nurses: 0808 801 0899

(Monday to Friday 9.30am-4pm)

Email: adviceline@chss.org.uk

Website: www.chss.org.uk

Disability Now

6 Market Road

London N7 9PW

Tel: 0207 619 7323

Website: www.disabilitynow.org.uk

Family Planning Association

23-28 Penn Street

London N1 5DL

Tel: 0207 608 5240

Website: www.fpa.org.uk

LGBT Foundation

5 Richmond Street

Manchester M1 3HF

Tel: 0345 3303030

Website: www.lgbt.foundation

Relationships Scotland

18 York Place

Edinburgh EH1 3EP

Tel: 0845 119 2020

Website: www.relationships-scotland.org.uk

The Sexual Advice Association

224, Building 3, Chiswick Park

566 Chiswick High Road

London W4 57A

Tel: 0207 486 7262

Website: www.sexualadviceassociation.co.uk





Chest Heart & Stroke Scotland welcomes your comments and feedback on this resource to help us to develop the best information for you and others who have had a stroke.

If you have any comments regarding this booklet or any of our other publications you can contact us through:



www.chss.org.uk



healthinformation@chss.org.uk



Rosebery House, 9 Haymarket Terrace
Edinburgh EH1 2 5EZ

PERSONAL STORIES

We would also like to hear from you if you would like to tell us about your experience of living with a stroke, or of caring for someone who has had a stroke.

Chest
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Advice Line Nurses



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

Helplines
STANDARD

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



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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

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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