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Stroke  
association

you're  
not  
alone

**Coping with the emotional effects of stroke -  
a practical guide for stroke survivors and carers**

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# Emotions and stroke — how we can help

A stroke happens in an instant but its effects can last a lifetime. Many people go on to make good recoveries but because stroke affects each person differently, it's important to get the support that's right for you.

Whether you've had a stroke, or you're the carer or family of someone who has had one, the worries and fears stroke brings can seem overwhelming. You may also be finding it hard to see how things can get better and it may also be affecting relationships between loved ones.

Many people hide these fears, unable to share them. Often this is for very understandable reasons – coping with the physical impact of stroke, shock, guilt, anger, frustration and not wanting to burden friends and family. And if you're a young stroke survivor, or the parent of a child who's had a stroke, it can be even tougher.

***Whether you're a stroke survivor, a family member or a carer, finding help when you're feeling this way can help you gain more control and start to change things for the better.*** Helpful information often gets overlooked immediately after stroke as people are overwhelmed, or don't have time to find it and take it all in – so we hope this leaflet will point you in the direction of the right emotional support for you.



## Express yourself

People affected by stroke often feel like they're on their own. But it doesn't have to be this way. You're not alone. There are lots of sources of support that many people find make all the difference. Expressing your feelings and finding support is the first step towards feeling better.

"I'd say to anyone in my situation try not to panic, and take the support offered. Don't think your life is over if you have a stroke."

**Claire Simpson, stroke survivor**



# Whatever you're feeling, it's ok

If your emotions or behaviour have changed since your stroke, or you feel different, it may be caused by the effect your stroke had on the part of the brain that controls emotions. It's normal to experience a change in your emotions after any difficult or traumatic life experience. Stroke happens without warning and it takes time to adjust to the changes it can bring to everyday life.

Don't be surprised if you feel shock and anger at what's happened. Fear of another stroke, despair, frustration and grief for things you've lost are natural emotions if you or a family member has had a stroke. You may feel depressed, anxious and you may become more emotional than usual.

Sometimes stroke survivors may have inappropriate emotional responses to stressful situations. Don't worry – it's common to go through a period of expressing emotions very differently, for example laughing at inappropriate times or saying things that may seem hurtful or confusing to others. These feelings can be the result of the stroke itself, or be part of adjusting to the way the stroke has changed your lives.



## Some common thoughts and feelings

Low mood, stress, lack of confidence, anger and relationship problems are challenges shared by many stroke survivors and their families. You may be going through a form of grief for the life you had before the stroke, find it hard to cope at work, or feel your friends have turned their back on you.

It's also common for family life to become stressful after stroke as changes occur in people's roles as mediators, breadwinners, bill-payers, or the parent most likely to maintain family discipline. Young stroke survivors may worry about exams, bullying, dating, not being able to do sport, learning to drive or even leaving home.

Added to this emotional rollercoaster is frustration at not being able to complete simple, everyday tasks such as communicating, driving, shopping, dressing or washing. Stroke survivors and carers often feel tired, unable to get time to themselves (though still feeling isolated), and cut off from advice.

Your thoughts may turn to: *Will I get back to how I was before? What happened to the person I married? Why me?* There are no easy answers to these questions, but it's normal to ask them. **The real answer to coping with these feelings is accepting that they're normal and finding help – there's much more of it available than you might think.**

# Coping with emotional changes

Our research shows nearly every stroke survivor experiences emotional difficulties after stroke. Often these problems improve with time, and you may begin to feel more like yourself again quite quickly, but some emotional problems may take longer to overcome.

## Anxiety and loss of confidence

After a stroke it's very common to feel anxious. Maybe you're worrying about being unable to care for your family, and what will happen to your job – how long you can have off work, will you be accepted back, and will you get the time you need to get better? You may also be worried about the effect on close relationships (some people feel rejected by their partner, even though they haven't been), or about having another stroke.

**What you can do:** A good start is to get information – being informed takes away much of the fear of uncertainty. Our Stroke Helpline can offer you support and information by phone or email (see page 11). We can tailor an information pack to your needs, check for support services in your area, point you in the right direction for advice about applying for benefits, put you in touch with local groups, and tell you how you can get online support from others living with stroke.

"People don't realise how life-changing a stroke is. Although therapy helped me recover physically – emotionally it was much harder."

**Brad Francis, stroke survivor.**

## Depression

Over half of stroke survivors say they experience depression in the first year after their stroke. If you're regularly experiencing a mix of feeling sad, losing interest in everyday activities, feeling worthless, finding it hard to concentrate, eating too much or too little, changes in your sleep pattern, thoughts of self-harm or loss of self-esteem, then you may have depression.

**What you can do:** Talk to your doctor - the sooner you find help, the sooner you're likely to feel better. Call or email us for our Depression after stroke factsheet (it's also on our website), which has lots of tips to help you manage your depression. If someone in your family is a young stroke survivor, our factsheets Childhood stroke and Stroke in younger adults offer information and tips on coping emotionally.

## Anger

After a stroke you might wear yourself out trying to do things you used to take for granted and get irritable at things that wouldn't normally bother you. You might direct this anger at your family and carers – this is natural, as emotions can escalate when people are tired and fed up, or have had a big change in their circumstances.

**What you can do:** Doing something physical if you can, like taking a walk, is a really good way to let off steam. If you're concerned about your anger, make an appointment with your GP who can refer you to a therapist or counsellor to help you talk things through.



# Being a carer can be emotionally draining too

Carers play a vital but often under-appreciated role and it can be very demanding, especially if you suddenly find yourself in the role. It may mean you have to be emotionally and physically strong when you feel least able.

## Isolation

Many carers tell us they sometimes feel exhausted and alone, especially as friends and family might not understand how tough it can be. Suddenly seeing a loved one unwell can be upsetting, and being thrust into a caring role without sufficient support can be difficult. You may feel a deep sense of loss, as the person you know and love may have changed. And sometimes, these changes can affect your feelings towards them.

**What you can do:** Talk to others. Meeting other carers, chatting online and getting support from those in a similar situation can help. Register as a carer with your GP and talk to your doctor or social worker – they can help you understand what to expect, and tell you more about stroke and the treatment of the person you care for. You can ask for a carer's assessment of your needs from your local council as a first step in getting practical support. Don't be afraid to be honest about what is happening and above all, don't think it's admitting defeat to take whatever help is available. Contact our Helpline to find out what carers' support might be near you (see page 11).



## Worries about work

Juggling a carer's role and other work or family responsibilities can be emotionally draining.

**What you can do:** Talk to your employer – explain that your situation is difficult. You might find they are much more understanding than you expect. You have a right to request flexible working and time off to look after dependents in an emergency.

"Being a carer can be incredibly hard. I felt like my husband's personality had completely changed and I felt very isolated. Talking to people in a similar situation helps enormously."

**Christine Blandford, carer.**



### Feel there's no 'me' time?

Caring for someone who's dependent on you is a huge responsibility and it's easy to forget your own needs. But it's realistic, not selfish, to think about taking care of yourself, because if you don't, you might get stressed or exhausted.

**What you can do:** While it might seem like a luxury, try to make time for yourself by doing things you enjoy. Perhaps it's going for a walk, swimming, gardening or simply going out for a coffee with a friend. Remember to eat healthy, proper meals. And try and get a good night's sleep – lack of sleep is a well-known cause of depression. You could also consider arranging respite care. This could be through friends and family, or using a care agency, employing a care worker directly or getting help from your local council.



# We're here for you

Whether you've had a stroke yourself or are a carer of someone who has had a stroke, getting information on finding the support you need is a good first step towards feeling better about the journey you're on. Here's where to start.

- Call the Stroke Helpline on **0303 3033 100** and talk to someone who understands what you're going through. We also have a textphone number that you can use if you have difficulty speaking (see page 14).

Whatever your question – *What's happened? What's likely to happen in the future? How do I live with the changes?* – we're here to help and give you the support you need. We'll also be able to tell you whether there's one of our **Life After Stroke Services** or similar support available near you.



- Join a local stroke club, where you can meet other local people going through similar things as you, share your experience and benefit from their understanding. These clubs provide valuable emotional support for carers, stroke survivors and relatives. Meetings are held regularly in local community centres, church halls or pubs, along with social events such as outings and quizzes.
- Visit our website for information on stroke; you can talk to other people who've been affected by stroke via our online forum TalkStroke, read people's success stories, and find out about local stroke groups and related services near you. You can also take a look at our range of practical products designed to promote independence and support you.

"I heard about the Stroke Association on the radio, and they sent me a lot of information. Life improved for me dramatically the day I went to my first stroke club."

**Irene Thompson, stroke survivor**



- If you are interested in helping to shape stroke services, why not join our Campaigners' Network. You can team up with others taking action to get a better deal for stroke survivors and their carers. Visit **[stroke.org.uk/campaigns](http://stroke.org.uk/campaigns)**
- Are you on Twitter or Facebook? Thousands of stroke survivors and their carers are following the Stoke Association and supporting each other and sharing tips and information via Twitter and Facebook. Why not join us at **@TheStrokeAssoc**, and at **[www.facebook.com/TheStrokeAssociation](http://www.facebook.com/TheStrokeAssociation)**



## Resources to help you cope with emotions after stroke

A full list of useful organisations is also included in the following Stroke Association publications:

- *Emotional changes after stroke*  
– item code A01F36
- *Depression after stroke*  
– item code A01F10
- *Stroke: A carer's guide*  
– item code A01F04
- *Childhood stroke*  
– item code A01F34
- *Stroke in younger adults*  
– item code A01F09

We also publish a wide range of other leaflets to help people to cope with life after stroke, including the *Stroke survivors' Declaration*. All of our publications can be ordered from the Stroke Helpline, or downloaded or ordered from our website at **[stroke.org.uk/information/resource-library](http://stroke.org.uk/information/resource-library)**

# Getting help

## Stroke Association

**Stroke Helpline:** 0303 3033 100

**Email:** [info@stroke.org.uk](mailto:info@stroke.org.uk)

**Website:** [stroke.org.uk](http://stroke.org.uk)

**From a text phone:** 18001 0303 3033 100

## Other organisations ready to help:

### Carers UK

Advice, support and information for carers

**Telephone:** 0808 808 7777

**Email:** [advice@carersuk.org](mailto:advice@carersuk.org)

**Website:** [www.carersuk.org](http://www.carersuk.org)

### Connect

Expert counselling for people living with stroke and aphasia

**Telephone:** 020 7367 0840

**Email:** [info@connect.org](mailto:info@connect.org)

**Website:** [www.ukconnect.org](http://www.ukconnect.org)

### Different Strokes

For younger people affected by stroke

**Telephone:** 0845 130 7172 or 01908 317618

**Email:** [info@differentstrokes.co.uk](mailto:info@differentstrokes.co.uk)

**Website:** [www.differentstrokes.co.uk](http://www.differentstrokes.co.uk)

### Mind

Resources and support for mental health

**Mind infoline:** 0300 123 3393

**Email:** [info@mind.org.uk](mailto:info@mind.org.uk)

**Website:** [www.mind.org.uk](http://www.mind.org.uk)

## **Mind Cymru**

**Telephone:** 029 2039 5123

**Email:** [contactwales@mind.org.uk](mailto:contactwales@mind.org.uk)

**Website:** [www.mind.org.uk/mind\\_cymru](http://www.mind.org.uk/mind_cymru)

## **Relate**

Relationship support

**Telephone:** 0300 100 1234

**Website:** [www.relate.org.uk](http://www.relate.org.uk)

## **Relationships Scotland**

Provides relationship support throughout Scotland

**Telephone:** 0845 119 2020

**Email:** [enquiries@relationships-scotland.org.uk](mailto:enquiries@relationships-scotland.org.uk)

**Website:** [www.relationships-scotland.org.uk](http://www.relationships-scotland.org.uk)

## **Samaritans**

Someone to talk to – people contact us when things are getting to them

**Telephone:** 08457 90 90 90

**Email:** [jo@samaritans.org](mailto:jo@samaritans.org)

**Website:** [www.samaritans.org](http://www.samaritans.org)

## **Scottish Association for Mental Health**

Information and advice on mental health

**Telephone:** 0800 917 3466 (2-4pm Monday to Friday)

**Email:** [info@samh.org.uk](mailto:info@samh.org.uk)

**Website:** [www.samh.org.uk](http://www.samh.org.uk)

## **Speakability**

Offering information and support for people affected by aphasia

**Telephone:** 080 8808 9572

**Email:** [speakability@speakability.org.uk](mailto:speakability@speakability.org.uk)

**Website:** [www.speakability.org.uk](http://www.speakability.org.uk)





## **We are the Stroke Association**

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research into finding new treatments and ways of preventing stroke.

**We're here for you. If you'd like to know more please get in touch.**

**Stroke Helpline:** 0303 3033 100

**Website:** [stroke.org.uk](http://stroke.org.uk)

**Email:** [info@stroke.org.uk](mailto:info@stroke.org.uk)

**From a textphone:** 18001 0303 3033 100

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