

Life after stroke

Depression and other emotional changes

Together we can conquer stroke

Most people who have had a stroke will experience some kind of emotional change afterwards.

In this booklet we talk about some of the most common emotional changes people experience after a stroke, why they happen and what you can do about them.

It's aimed at people who have had a stroke but there is information for family and friends as well.

We have information on all aspects of stroke.

If you have a question that is not answered in this booklet, visit **stroke.org.uk** or call our Stroke Helpline on **0303 3033 100**



If you want more information on this topic, take a look at our *Complete guide to emotional changes after stroke*. Go to **stroke.org.uk/publications** to find it.

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Why do I feel different?



A stroke is sudden and shocking and affects every part of your life. It's a lot to deal with, not just for you but for everyone around you too.

Everyone's experience of stroke is different, but for many people it feels like they've lost the life they had before.

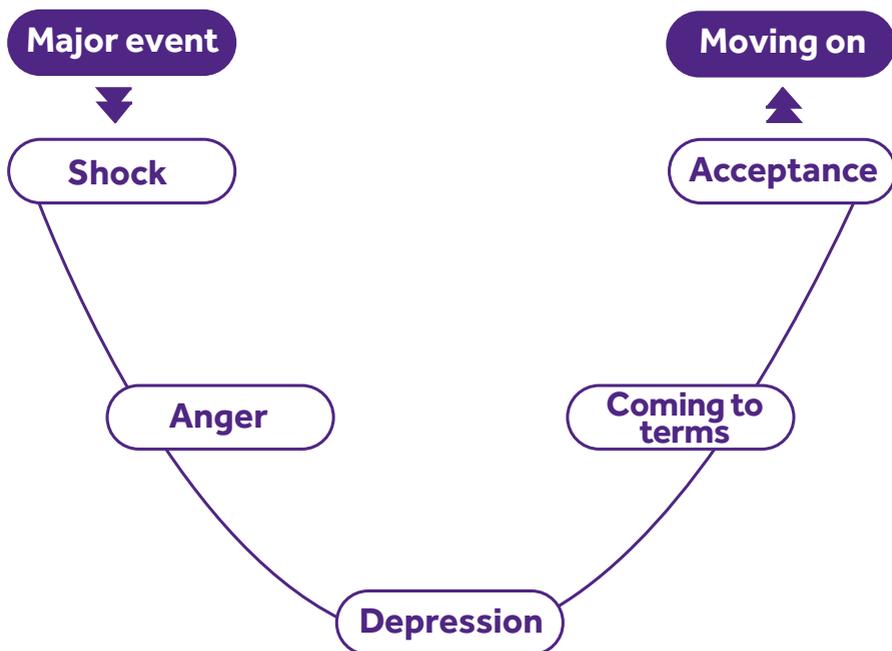
Feelings of **shock, denial, anger, grief and guilt are normal** when you're faced with such a devastating change. Dealing with these feelings can be hard and everyone does it differently. What can make it harder is that the people around you may not realise what you're going through.

"If I had a penny for the amount of times people say 'you don't look like you've had a stroke.' On the plus side it must mean I look well but the downside is people don't have a clue what I'm going through daily."

John-Lee

Often people don't want to admit how they're feeling after a stroke and put on a brave face. But if you don't **acknowledge the way you're feeling** and find things that can help you deal with it, these emotions can become overwhelming and lead to problems like depression or anxiety.

The stages of loss



Adapted from Stages of the Grief Cycle by Kübler-Ross, 1969

What kinds of problems can this cause?



Anxiety

It's normal to feel anxious after a stroke – you may worry that you're going to have another one, or be frightened about getting around on your own. You may also be worried about money or your family. These fears are all perfectly normal and you should feel less anxious about them over time.

If you're becoming **anxious about a wide range of things**, or if you can't tell what you're feeling anxious about, then you should speak to someone about it. It can affect your recovery if you're always anxious, so make sure you get some help.



Frustration and anger

So many things change after a stroke, and so quickly, that it can be hard to accept. Feeling angry or frustrated about this is normal and you're going to feel this way from time to time.

But if you don't deal with these feelings properly, they can **build up and affect your mood** and the way you behave towards other people. It can also affect your health and recovery if you're angry all the time.



Difficulty controlling your mood and emotions

A stroke can affect your ability to control your mood and emotions. This is called **emotionalism** or emotional lability.

It can mean that **your mood changes very quickly**, sometimes for no reason at all. It can also mean that you're more emotional than you used to be and **you cry or laugh** at even the smallest things. Some people start to swear, when they hadn't used to before.

It can be upsetting, especially if you weren't an emotional person before your stroke. Some people say they feel embarrassed, so they stop going out or try to avoid social situations.



Depression

It's normal to feel down or hopeless after a stroke. But depression is when **feelings of hopelessness and sadness** don't go away.

They last for weeks or even months and if they do go away they may come back, over and over again. Because of this, they can begin to affect your sleep, appetite and interest in life.

Depression can appear at any point, perhaps months or even years down the line. But if you know the signs and understand that the way you're feeling may be down to depression, it can help you realise that you need some support.



Severe depression is very serious. It can make you feel that you want to give up on life and you may think about harming or killing yourself.

If you've had feelings or thoughts like this, then you need to **speak to your doctor straight away** and get some support.

Will it get better?



When emotions are overwhelming it can be easy to think that they'll never get better. But they do.

Feeling low, anxious or angry, or not being able to control your emotions are all very common after a stroke, especially in the first few months. However, this will probably get better as time goes by.

Even if these feelings never completely go away, you'll probably find them easier to live with over time. And remember, **you're not on your own**. There are lots of people who are there to help you.

“Support isn't always offered, but it is out there, so ask. You need to get all the help you can.”

Jocelyn

What can I do about the way I feel?



Get some help

There's a lot to cope with when you've had a stroke, so don't be afraid to ask for some help.

If you're worried about the way you're feeling, or you think you may be experiencing some of the problems we've described, then you need to **speak to your doctor** about it. They will be able to tell you about the support that's available.

It can be easy for people, including doctors, to forget that there are effects of stroke you can't see. Sometimes they can miss emotional problems or don't take them seriously. So **don't wait to be asked** about them and keep pushing to get the support you need.

If you don't think you're getting the right help from your doctor or stroke team, then contact our Stroke Helpline.



How your doctor can help

There are a number of treatments and therapies that can help with your emotions after a stroke.

Depending on the problems you're having, it may be good for you to talk to someone who specialises in mental health, such as a psychologist or counsellor. Your doctor will be able to refer you to one.

Your doctor may also recommend **talking therapy** to you. Talking therapy gives you time and space to talk about difficult feelings with a trained therapist. This can help you deal with specific problems or develop ways of coping with your thoughts and feelings.

Therapists can work with you one-to-one or jointly with your partner or other family members. Group therapy sessions are another option.

Unfortunately, talking therapy through the NHS can vary a lot from area to area. Sometimes the waiting list can be long. So speak to your doctor about what your options are.

There may also be **medication** that can help you with your emotions. Antidepressants are drugs that affect the chemicals in your brain and lift your mood.

Antidepressants don't cure emotional problems, but they can help with the symptoms and make life feel easier. They don't work for everyone and can also have side effects.

There are lots of different types of antidepressants and it can take a bit of time to find the right one at the right dose. So if it's something you decide to try, you'll need to work with your doctor to find what's best for you.

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Talk to someone about it

Talking about the way you're feeling with someone who understands can really help. You may want to do this with a **counsellor or therapist** or it could be a **family member or friend** – whoever you feel most comfortable confiding in.

Many people also find **support groups** helpful, because you can talk about your problems with people who are going through the same thing. Stroke clubs and groups are a good way to meet other stroke survivors and get advice and support, but there are all sorts of groups out there.

“I wasn't able to cope with it all on my own. Talking to my doctor and getting some counselling was the best thing I ever did.”

Craig

A stroke can make you feel that you're not in control any more. But talking to the right people and **finding answers to your questions** will help you feel more in control.

The fear of having another stroke can cause a lot of worry, so **talk to your doctor**. Find out what they think caused your stroke and what you can do to reduce the risk of it happening again. Don't be afraid to ask questions. It's important that you understand what's happened and why.

If you're worried about not being able to go back to work, talk to your occupational therapist about it. Finding out what **financial support** you can get will also help to ease your fears. Speak to your social worker if you have one or call our Stroke Helpline.



Communication problems can make it difficult to ask questions, but your speech and language therapist can help you talk to other members of your stroke team, if that will help you get the information you need.

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Take it easy on yourself

Many people find that they have to learn what's 'normal' for them again after they've had a stroke. This means listening to both your body and your brain and not expecting yourself to do too much, at least not to begin with.

There's **no need to be embarrassed** about the way you're feeling – there's a lot to cope with. Be honest about the problems you're having. Often people just want to know how they can help, so they'll appreciate it if you tell them.

Don't be afraid to **ask for support** when you need it, especially if you're having problems with emotionalism. Your family and friends may not be able to tell when you are actually upset and when you're not, so make sure you let them know.

“Accept that you're going to have bad days and don't push yourself too hard when you do. Take each day as it comes.”

Michelle



Keep going

Many people feel that they lose their sense of purpose after a stroke. This can really affect your confidence and make you feel down. That's why it's important to stay connected to the people and things in your life as much as possible. This can be hard, as you may not be able to do everything that you did before. But there will be **things that you can do**, so focus on these.

Set yourself **small goals** to work towards, one step at a time. Keep track of the progress you make, as it can be easy to forget, especially if things don't happen as quickly as you'd like.

It can be particularly hard if you worked or were involved in lots of things before your stroke. But you need to remember that there are still opportunities out there, you may just need to **find other ways to use your skills and talents**. Many people find that volunteering, taking part in research, or finding new interests help them to feel useful again after their stroke.

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Get it out

Writing things down can help you deal with negative thoughts and feelings. Many people find that **keeping a journal** helps them – it doesn't have to be written, you could keep a video journal instead. Things like art, music, photography or poetry can give you a way of expressing your feelings as well.

If you're becoming frustrated or angry you need to find ways to **release the tension** you're feeling. That way you can focus your energy on more positive things, like getting better. Doing something physical can help you let off some steam. Even simple things like pounding a pillow or allowing yourself to have a good cry can help get it all out too.



Many people find that **relaxation or meditation** helps them to calm down when their feelings get too much. There are plenty of books, CDs, websites and courses that can teach you about relaxation and meditation. Try asking your local library or stroke group for recommendations.

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Try to be as active as you can

Although you may not feel up to it, it's important to be as active as you can. When we're active our body releases chemicals into our brain that make us feel happier. Just a **short walk** or a bit of gardening can have a good effect – whatever you can manage.

If you're not able to get up and about, practising your physiotherapy exercises will help. Or you could try some **chair-based exercises**. Your physiotherapist will be able to show you some.



Yoga and tai-chi involve gentle exercises and relaxation. So why not give them a go? Even if you have problems with moving around or with balance, many of the movements can be adapted. Speak to a local instructor.

Where can I get help and support?

If you're worried about the way you're feeling, speak to your **doctor**.

How we can help



Our **Stroke Helpline** can give you information and support on any issue you or your family may be facing after stroke. Whatever the problem, we're here to help.



We have **coordinators** in some areas of the UK, who can give you and your family information, practical advice and emotional support. We also run **stroke groups** across the UK. Even if we don't run one in your area, we can tell you about others that do.



Or you can talk to other people affected by stroke on our online forum TalkStroke or on our Facebook page. Visit **stroke.org.uk/talkstroke** or **facebook.com/TheStrokeAssociation**

To find out how we can help, just get in touch:

- call our Stroke Helpline on **0303 3033 100**
- email **info@stroke.org.uk**
- visit **stroke.org.uk**

Other organisations that can help

The following organisations can provide information, advice and support. Contact our Stroke Helpline if you'd like to know about others in your area.

MIND/ MIND Cymru (England and Wales)

Website: www.mind.org.uk

Infoline: 0300 123 3393

Email: info@mind.org.uk

Niamh Wellbeing (Northern Ireland Association for Mental Health)

Website: www.niamhwellbeing.org

Tel: 028 9032 8474

Scottish Association for Mental Health

Website: www.samh.org.uk

Tel: 0141 530 1000

Email: enquire@samh.org.uk

Samaritans offer emotional support over the phone 24 hours a day, 365 days a year.

Website: www.samaritans.org

Tel: 08457 90 90 90

Email: jo@samaritans.org

Tips for family and friends

It can be difficult to know how to help someone with their emotions after a stroke. So here are some suggestions.



Talk to each other

Sometimes it's hard for people to talk about their feelings, even with someone close. So let them know that you're willing to listen and **ask them what you can do** to help. Sometimes there won't be anything you can do, which can be hard. But just being there for them and encouraging them to seek help if they need to, is often all it takes.



Spend some time with them

Coping with the effects of stroke can make people feel very lonely. So simply spending some time with your friend or family member can really help. You may not have time to visit them as often as you'd like, but **even a short phone call** will show them that you're thinking about them.



Don't do everything

It's normal to want to do as much as possible for someone you love. But it will be better for your friend or family member if you **help them to do things on their own** rather than do all it for them. So encourage them to give things a go. Although they may not think they'll be able to, more often than not they'll be pleasantly surprised.



Help them stay active

Being active helps to lift our mood, so encourage your friend or family member to do whatever they can. It will help if you **do it together**. Even if they can't get up and about, there may be chair-based exercises they can do and they're likely to have exercises to practise if they're having physiotherapy.



Be patient

It takes time for things to improve, so you'll need to be patient. This isn't always easy, especially when you're coming to terms with everything that's happened as well. So make sure **you're looking after yourself** and have someone to talk to too.

About our information

We want to provide the best information for people affected by stroke. That's why we ask stroke survivors and their families, as well as medical experts, to help us put our publications together.



How did we do? To tell us what you think of this guide, or to request a list of the sources we used to create it, email us at **feedback@stroke.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 to develop 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

Email: info@stroke.org.uk

From a textphone: 18001 0303 3033 100

Text **STROKE 5** to **70300** to donate **£5**. It only takes a couple of seconds to make a BIG difference.

For more information visit stroke.org.uk/savelives

Texts cost your donation amount plus one message at your standard network charity rate. The Stroke Association will receive 100% of your gift. Always ask the bill payer's permission. For questions about donating by text call 0330 6600 425.

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