Life after stroke

Changes to your behaviour

Together we can conquer stroke
Because there is so much to deal with after a stroke, it’s normal for your behaviour to change in some way.

In this booklet we explain why your behaviour may change and talk about some of the things that can help you and the people around you cope with it.

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
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The way we behave often depends on the way we feel. A stroke is sudden and shocking and there are lots of emotions to deal with when you have one. It’s normal for this to affect your behaviour.

But it’s not just about the way we feel. We’re constantly receiving information from the world around us, which our brain has to understand, organise and keep. This is called cognition.

Our brain uses this information to adjust the way we think and react. If the part of your brain that processes this information is damaged by your stroke, this can change the way you behave as well.

Other effects of stroke can also affect your behaviour. Pain can make you irritable, for example, and if you’re constantly tired you may not be as sociable as you used to be. Frustration at not being able to do things for yourself can build up and make you angry or even aggressive towards others.
What kinds of problems can this cause?

Apathy
Apathy is when you lack motivation. You may lose interest in life and not want to take part in everyday activities. Things that you’d usually respond to, like good news or seeing someone upset, may not make you feel anything at all.

Apathy is fairly common after a stroke, although it’s more likely to affect you if you have severe physical or cognitive problems after your stroke. It can be a sign of depression, but it can also happen on its own.

Anger and aggression
Many people find themselves getting frustrated and angry after their stroke. You may lose your temper for no reason or get angry about things that never would have made you angry before. If your anger turns into aggression, you may shout, throw things, threaten people or try to hurt them.

Aggressive behaviour puts you and other people at risk. So it’s essential that you get some support to help you learn how to manage it.
Inappropriate behaviour
People usually think that behaviour is inappropriate when it ‘breaks the rules’ and makes other people feel uncomfortable. This can happen after a stroke for a number of reasons:

• if you **lose the ability to read social situations** you won’t know what’s expected of you, so you may stand too close to other people, interrupt them when they’re talking or not respond to their body language

• you may **not be able to think decisions through** properly, so you may make tactless remarks, act impulsively or spend money unwisely

• you may also **lose some of your inhibitions**. If this happens you may seem more self-centred and refuse to do anything you don’t want to. This can also affect your sexual behaviour, so you may crave more physical intimacy or make inappropriate comments to other people.
It’s normal for your behaviour to change in some way after a stroke. This is likely to get better as you recover and come to terms with what’s happened.

Some changes can be long-term, but this isn’t always a problem. Some people think that if you’re behaving differently to how you did before your stroke, then this needs to be ‘fixed’. But it depends entirely on the way your behaviour has changed. You may just need to give the people around you some time to get used to it.

If you’re behaving aggressively or inappropriately, however, you do need to do something about it. The information on the next few pages will help.
Listen to others
It’s very difficult to see changes in our own behaviour. So if you’re acting differently your friends and family are probably going to be the ones to notice. That’s why it’s important to listen to them if they bring it up.

People often talk about their loved one’s ‘personality’ changing after a stroke or claim that they’ve ‘become a different person’. It can be upsetting if your family or friends say this about you. However, what they’re really noticing are changes to your behaviour, not who you are as a person – a stroke can’t change who you are.

Give it time
Some change to your behaviour is to be expected, and although it may be difficult to live with at times, it’s likely to improve. Many people find that they have to learn what’s ‘normal’ for them again after they’ve had a stroke. This will take time, for you and the people around you.
Talk to someone
Talking about the way you’re feeling with someone who understands can really help. You may want to do this with a professional, such as 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.

If the change to your behaviour is extreme, or you start to behave in ways that may hurt or offend other people, you need to speak to your doctor to get some help with it.

“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
How your doctor can help

The way you’re behaving may be a sign of emotional problems, such as depression or anxiety. So your doctor will be able to look into other possible causes and talk to you about the best way to treat them.

They may also be able to refer you to a clinical neuropsychologist. This is someone who specialises in the way the brain works. They can carry out a detailed assessment to see if there are any cognitive problems that may be causing you to behave differently.

Your doctor should be able to tell you about other sources of support, especially if you’re becoming aggressive or behaving inappropriately.

Your doctor may recommend talking therapy to you, for example. Talking therapy gives you time and space to talk about difficult feelings with a trained therapist and think about how they may be affecting your behaviour.
What can I do if I’m becoming aggressive?

1. Learn your triggers

Talk to your friends and family to work out what makes you angry and how you can avoid it. If it tends to happen when you’re tired, for example, then make sure you get more rest or do things earlier in the day when you have more energy. Or if it happens when you’re bored, try to keep busy and plan ahead so you don’t end up with days when there’s nothing to do.

2. Develop a strategy

Agree a word, phrase or sign that your family and friends can use to let you know that you need to calm down. Or agree that they should walk away when you become aggressive and leave you on your own for 15 minutes.

“I’m constantly starting arguments with my partner. But now he tells me when I start getting stressy and that’s my signal to go off and have a quiet moment to myself.”

Dawn
What can I do if I’m behaving inappropriately?

1. Don’t ignore it
   The way you behave will seem entirely normal to you, even if it seems inappropriate to everyone else. So it’s important to listen to the people around you. It may not mean that the way you’re behaving is wrong, but it may mean you need to try to manage it a little better and help your family and friends adjust to it.

2. Try talking therapy
   Cognitive behavioural therapy (CBT) is a type of talking therapy that focuses on your thinking and behaviour and how they are connected. CBT may help you to learn how to think through your actions and understand the affect they can have on other people.

   A therapist could also work with your family members, to help them adjust to your change of behaviour and help you all find a way to be comfortable with it.
If you or your family are worried about the way your behaviour has changed, then **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**
The following organisations can provide information, advice and support. If you’d like to know about others in your area, contact our Stroke Helpline.

**Headway** is a charity for people who have had a brain injury. It has information for survivors as well as family, friends and carers.

**Website:** www.headway.org.uk  
**Helpline:** 0808 800 2244  
**Email:** helpline@headway.org.uk

The **Brain and Spine Foundation** supports people affected by brain and spine conditions, including stroke. Its helpline is run by nurses who specialise in brain conditions.

**Website:** www.brainandspine.org.uk  
**Helpline:** 0808 808 1000  
(Mon–Thu, 9am–2pm; Fri, 9am–1pm)  
**Email:** helpline@brainandspine.org.uk
It can be difficult when someone you love starts to behave differently, especially if they’re being aggressive or behaving inappropriately. Here are some tips to help you.

**Talk about it in the right way**
If your friend or family member is behaving in a way that upsets you, you have a right to tell them. But be careful not to make them feel that they are the problem. Keep your **focus on their behaviour** and how it makes you feel – say “It upsets me when you shout” rather than “You’re always upsetting me.”

**Don’t do it all on your own**
Get as much support as you can. Call our Stroke Helpline or **talk to your GP** to see if there are any services in your area that can offer support. Talking to a **therapist or counsellor** may help you come to terms with the changes. It can also help to talk to someone who’s gone through the same thing. So go along to your local **stroke or carers’ group**, where there may be people who have dealt with a similar situation and can offer advice.
Dealing with apathy (see page five)

Plan the day
Having a structure to the day can sometimes help people with apathy. It’s likely that your friend or family member will need a lot of encouragement to help them start and finish tasks, but if you stick to a routine, it could help them remember what to do.

Be patient
Apathy can be very difficult to deal with. It can feel as if your friend or family member has completely changed. But remember, they are still the same person and it’s likely to get better with time. Make sure you speak to your doctor about it and get the support you need.

“Neil’s still not the man I married but he’s slowly coming back; he’s becoming ‘him’ again.”
Ann
Dealing with anger or aggression (see page five)

**Listen**
Very often people can lash out because they feel ignored or not in control. So make sure you listen to your friend or family member and involve them when making decisions – even if they can’t make their own lunch, they may still want to choose what they have to eat.

**Don’t put yourself at risk**
It’s essential that you look after your own safety, so don’t feel bad about walking away if you need to. Just because someone has had a stroke, it doesn’t give them the right to hurt you. If your friend or family member becomes verbally or physically aggressive, try not to raise your voice (it won’t help if you become angry too) and leave them alone until they’ve calmed down.
Dealing with inappropriate behaviour
(see page six)

✅ Explain what’s acceptable and what’s not
If your friend or family member is acting inappropriately make it clear that their behaviour is not acceptable. **Be firm but not rude** – remember they won’t be doing it deliberately. Make sure you tell them when they do act in the right way.

✅ Get everyone on board
Being consistent is important, so **talk to other friends, family members and carers** to ensure that they deal with inappropriate behaviour in the same way. It will help to get the message across if everyone says the same thing.

✅ Be willing to compromise
Just because your friend or family member’s behaviour has changed, it **doesn’t automatically make it wrong**. It may just be a matter of adjusting to it. So talk honestly about it with them and find a compromise that you’re both comfortable with.
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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