

stroke.org.uk

Stroke
association

A complete guide to

Emotional changes after stroke



A stroke is sudden and shocking. This guide can help you understand the effect this could have on the way you feel.

It explains how a stroke can affect your emotions, some of the problems that this can cause 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 guide visit **stroke.org.uk** or call our Stroke Helpline on **0303 3033 100**.



What's in this guide?

Why do I feel different?	4
What kinds of problems can this cause?	5
Anxiety	5
Frustration	6
Anger	6
Depression	6
Difficulty controlling your emotions (emotionalism)	7
Mania and euphoria	7
Will it get better?	8
Are there treatments that can help?	9
Talking therapy	9
Medication	10
What can I do about the way I feel?	11
What can I do about depression?	14
What can I do about anxiety?	14
What can I do about emotionalism?	15
What can I do about feeling frustrated or angry?	15
Where can I get help and support?	16
How we can help	16
Other organisations that can help	16
Tips for family and friends	18

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 so it's going to have an effect on the way you feel.

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 them can be hard and everyone does it differently.

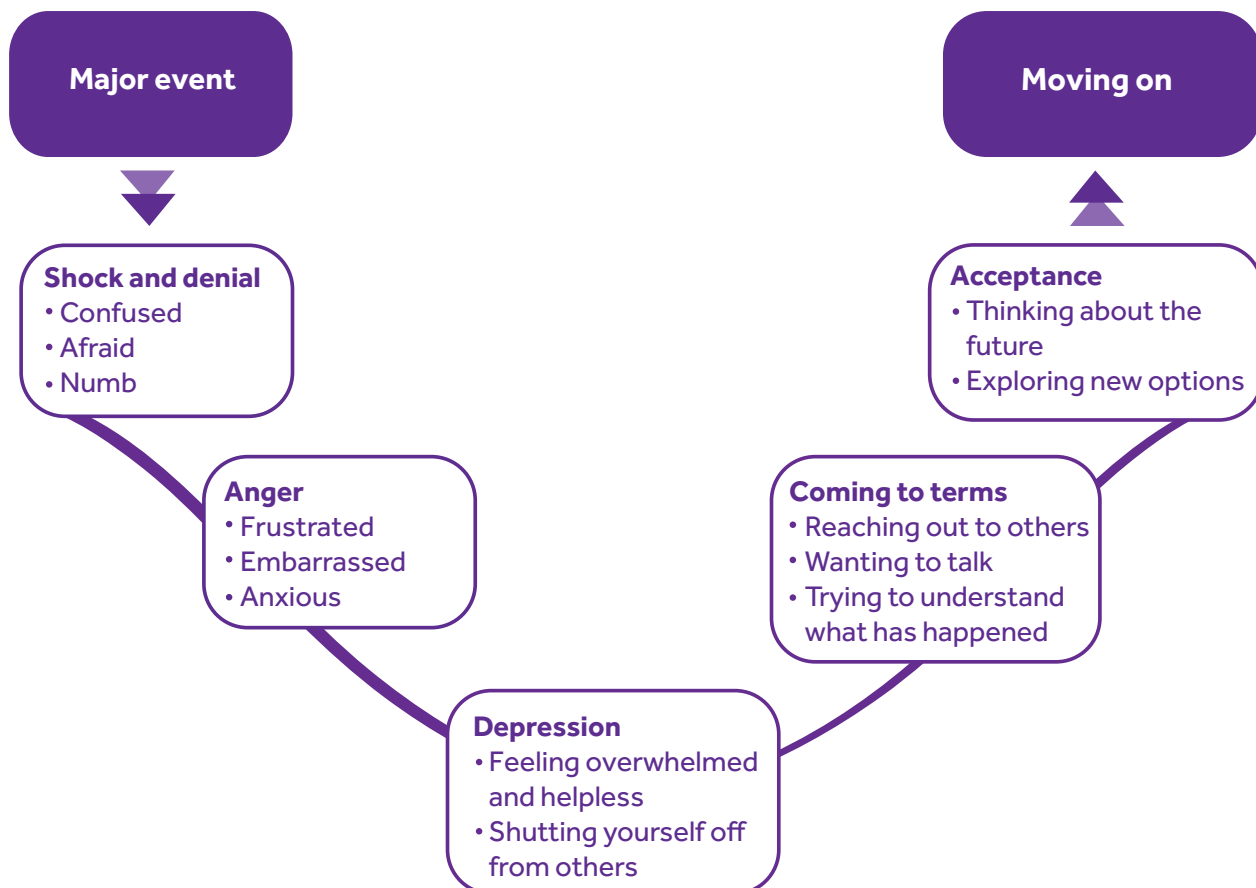
Not only are you going through all these emotions yourself, but the people around you will be too. Often people don't want to admit how they're feeling and put on a brave face. So the people around you may not realise what you're going through.

They may assume that everything is fine, which can make it hard to tell them if it's not. Communication problems may mean that you can't explain how you're feeling, even if you want to.

All of this can be difficult to cope with. 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.

Sometimes the damage that a stroke does to your brain can make you feel differently as well. Different parts of your brain control different things. If the part of your brain that controls your emotions is damaged, then this can affect how you feel.

The stages of loss



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

What kinds of problems can this cause?

Anxiety

It's normal to feel anxious after a stroke. Around one quarter of people who have a stroke will experience some form of anxiety within the first five years.

You may worry that you're going to have another stroke 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.

"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

Signs of anxiety

We all experience slightly different things when we're anxious, but you're likely to notice some of the following:

- feeling restless
- a sense of dread
- feeling on edge
- difficulty concentrating
- a racing heartbeat
- trembling or shaking
- feeling short of breath
- a dry mouth
- feeling sick or 'butterflies' in your stomach
- an urgent need to go to the toilet.

It may not always be clear what you're anxious about, which can make these feelings worse. Severe anxiety can be overwhelming. It can make you feel powerless or out of control, as if you are about to die or go mad. You may also experience panic attacks.

If you continue to have problems with anxiety, these are some of the long-term symptoms you may notice:

- tiredness
- not going out and avoiding new situations
- problems sleeping
- tense or aching muscles
- being irritable with other people.

Frustration

One of the emotions that nearly all stroke survivors have to deal with is frustration. So many things change after a stroke, and so quickly, that it can be hard to accept.

You may feel frustrated about:

- not being able to do what you used to do
- having to rely on other people
- everything taking longer than it used to
- not being able to work or do other things
- not being able to go out
- not being able to express how you're feeling
- saying the wrong word
- making mistakes
- forgetting things
- feeling tired and having no energy.

Feeling frustrated is normal and you're going to feel this way from time to time. But if you don't deal with these frustrations properly, they can **build up and make you irritable**. This means you're likely to get annoyed very easily. You may lose your temper and your mood can change quickly, which can be difficult to live with.

Anger

You may get angry more often after you've had a stroke. You may **not be able to control your temper** and feel you become angry for no reason. Or you may get angry about things that never would have made you feel that way before.

Although some anger is normal, it can affect your health and recovery if you're angry all the time. It can also make life difficult for the people around you.

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.

Depression is very common after a stroke. We know that at least one third of stroke survivors will have some form of depression within the first year. But you may not have it straight away. It can appear at any point, perhaps months or even years down the line. It can also return over and over again. So it's important to know what to look out for and how to get help and support if you need it.

Signs of depression

Depression affects people in different ways, but these are some of the more common signs:

- feeling sad or down in the dumps
- feeling worthless, helpless or guilty
- feeling hopeless or desperate
- feeling anxious or worrying a lot
- losing confidence
- losing interest in things you used to enjoy
- lacking energy or motivation
- not going out or avoiding other people
- finding it difficult to concentrate or make decisions
- having problems sleeping or sleeping too much
- losing your appetite or eating too much
- losing interest in sex.

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 like this, you need to **speak to your doctor straight away** and get some support.

Difficulty controlling your emotions (emotionalism)

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 and you are more emotional than you used to be.

You may find that you cry or laugh more and this can become extreme, such as laughing at something inappropriate. Or it can happen for no reason at all. Some people start to swear, when they hadn't used to before their stroke.

Emotionalism is most common in the early stages of stroke, when about one fifth of people have problems with it. 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.

If you're more emotional it can be a sign of depression, but it can happen on its own too.

Signs of emotionalism

We're all different and, by nature, some people are more emotional than others. So signs of emotionalism depend entirely on what's normal for you. But these are some common signs:

- finding yourself crying or laughing for no reason
- expressing your emotions more intensely than you actually feel them
- feeling like you have no control over your emotions and that even the smallest thing can set you off
- having emotions that seem out of place or come and go very quickly.

Mania and euphoria

Mania is when your mood is extreme. It can be extremely high or extremely low and may swing between the two. Your energy and enthusiasm will change with your mood, so if it's high you'll seem hyperactive, you may talk very quickly, have lots of ideas and you may have difficulty sleeping. Mania isn't a common effect of stroke, but it does affect some people.

Some people also experience **euphoria**, which is when your mood is constantly high and you seem extremely positive. But, like mania, this only affects a very small number of people.



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. 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 cope with the way you're feeling. You don't have to do it alone.

"After a stroke your brain is your worst enemy – it will tell you that you're a burden and there's no hope. You have to fight it."

Tina



Are there treatments that can help?

Lots of **treatments and therapies can help with your emotions** after a stroke. Depending on the problems you're having, your doctor may be able to refer you to someone who specialises in mental health, such as a psychologist or a counsellor.

Many people find that talking about the way they're feeling helps them to be able to understand and deal with it. So your doctor may recommend talking therapy to you. Medication can often help as well.

Talking therapy

Talking therapy gives you time and space to talk about your problems and **explore difficult feelings with a trained therapist** – this could be a counsellor, psychotherapist, psychologist or a psychiatrist. 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.

There are different types of talking therapy. One that many people find helpful is **cognitive behavioural therapy (CBT)**. This can help with many of the emotions people experience after a stroke and is recommended as a treatment for depression and anxiety.

CBT focuses on your thinking and behaviour and how they are connected. Negative thoughts can stop you from doing things, which in turn, can make you feel worse. CBT can help you break this cycle and improve the way you feel. CBT usually needs a number of sessions, over the course of several weeks.

CBT at home

It's possible to teach yourself CBT and your doctor may suggest that you try this. There are lots of printed and audio books on the subject, which can guide you through exercises and techniques. There are also interactive computer and online programmes that you can try. Your GP or therapist may be able to recommend some suitable ones to you.

Although most of these resources won't have been developed specifically for people who have had a stroke, they're still likely to have lots of information that can help you.

Unfortunately, **talking therapy and counselling services through the NHS** vary a lot from area to area. Depending what services are available and how much demand there is for them, the waiting list could be long. On the other hand, your stroke team may have its own psychologist or access to special services that you can be referred to quite quickly.

Speak to your doctor about what your options are. In some areas you can refer yourself to talking therapy services. We've listed some websites on page 17 that you can use to look up what's in your area or contact our Stroke Helpline to find out.

Because you can wait a long time for therapy through the NHS, some people choose **private therapy**. This means finding your own therapist and paying for treatment yourself. Prices can range between £10 and £70 for one session, so this isn't an option for everyone. If you do decide to pay for private therapy, we suggest finding a therapist who has experience of working with people who have had a stroke. Contact us if you'd like to know more about private treatment.

Communication problems can make it very hard to express how you're feeling. But that shouldn't stop you from getting the emotional support you need. So if you're struggling with your emotions and would like to talk to someone about them, tell your speech and language therapist and ask what support is available for you.

Medication

Some drugs can help you with your emotions. **Antidepressants** are the most well known. These drugs affect the chemicals in your brain and lift your mood. This can help to treat depression and sometimes anxiety. Medication can often help if you're having difficulty controlling your emotions as well.

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 are usually best for people with more severe problems. They 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. They can also take a little while to work. So if it's something you decide to try, you'll need to persevere and work with your doctor to find what's best for you.



What can I do about the way I feel?

1

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.

Emotional problems are often missed by doctors and sometimes it can be difficult to get them taken seriously. However, you need to trust that you know yourself better than they do, so don't be afraid to keep pushing to get the support you need. If you don't think you're getting the right support from your doctor or stroke team, then contact our Stroke Helpline.

2

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

3

Stay informed

A stroke can make you feel low or anxious. But talking to the right people and finding answers to your questions will help you feel more in control. For many people, the fear of having another stroke can cause a lot of worry. So talk to your doctor about what they think caused your stroke and **what you can do to reduce your risk of it happening again**. Don't be afraid to ask, even if it's weeks or months later. It's important that you understand what's happened to you 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.

4

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.

"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

5

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.

6

Be as active as you can

When you're active your body releases chemicals into your brain that make you feel happier. Because of this, exercise has been proven to help with a number of emotional problems.

It doesn't have to be running or swimming, even a short walk or a bit of gardening can have a good effect. If you can't get up and about, **practising your physiotherapy exercises** will get you active or try some chair-based exercises.

Yoga and tai-chi involve elements of mindfulness and relaxation, as they encourage you to focus on your body and breathing. So why not give them a go? Even if you have physical problems, many of the movements can be adapted. Speak to a local instructor or contact your local stroke group and ask about suitable classes.

7

Try relaxation

Relaxation can help you cope when your emotions start to feel overwhelming. Research has shown that relaxation can be particularly helpful in treating anxiety after stroke. There are techniques you can learn to help you relax. These usually focus on breathing or releasing tension from your muscles.

Many people find that **mindfulness** or other forms of **meditation** help them too. These are techniques that encourage you to pay more attention to the present moment – to your own thoughts and feelings as well as your body and the world around you. This can be especially helpful when you're feeling overwhelmed.

There are plenty of books, CDs, DVDs and websites that can teach you about relaxation and meditation. Although most of them won't have been designed for people who have had a stroke, there's still likely to be a lot that you can get from them and many stroke survivors do find them helpful.

There are also many courses on relaxation or mindfulness. Try contacting your local college or library to see if they can tell you about any in your area. Courses are provided by the NHS in some areas. So ask your doctor if there's anything available where you live.

“Rest your mind as well as your body.”

Patricia

8

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.



What can I do about depression?

- **Keep busy**
Although you may not feel like doing anything, being active can help you feel more positive. So however difficult it seems, at least try to give your rehabilitation exercises a go. You may find them easier than you think.
- **Be kind to yourself**
Write down the compliments that people give you and the achievements you make, so that you can go back and remind yourself of them when you're feeling down. And think about your appearance – looking good makes us all feel a little better. So treat yourself to a haircut or a manicure. If you can't get to a salon yourself, find someone who can come out to your house.
- **Eat well and avoid caffeine and alcohol**
If you're not eating much or you're comforting yourself by eating junk food all the time, then it's going to make you feel tired and run down. So try to eat regular meals with lots of fruit and vegetables and fish. Cut out alcohol and caffeine, as they can alter your mood and affect your sleep.

What can I do about anxiety?

- **Try relaxation**
Relaxation has been proven to reduce anxiety. Breathing techniques can be especially helpful when you find yourself becoming anxious. Some people find that mindfulness helps with anxiety too.
- **Keep busy**
Exercise encourages your brain to release chemicals that lift your mood, which helps to relieve stress and tension. Focusing on an activity can also help to take your mind off things and give you a distraction from negative thoughts or feelings.
- **Talk it through**
A support group means you can talk about your problems with people who understand because they are going through the same thing. There are groups for people who have had a stroke as well as groups for people coping with anxiety. Or speak to a friend or family member if you prefer. They can help you talk through the things that are making you anxious and put them into perspective.



What can I do about emotionalism?

- **Give it time**
Emotionalism does get better over time. Many people find that it improves or disappears altogether within the first six months. Even if your problems last longer than this, there are treatments and techniques that can help, so make sure you speak to your doctor about it.
- **Be open about it**
If you tell new people about your emotionalism when you first meet them, then you'll be less embarrassed if you do become emotional in front of them. People feel awkward if they don't know what to do, so they'll appreciate it if you tell them how to help you. You may prefer people to ignore it and just carry on as normal, or you may find a hug comforting when you get emotional. Lots of people have problems with emotionalism after a stroke, so talking to other stroke survivors can help as well.
- **Tell people when it's real**
You may have to tell people when you're genuinely upset, so that they don't mistake it for emotionalism. You're still entitled to comfort and support, so don't be afraid to ask for it.

“Talk to people close to you about what's happening. Explain to them that this is a change in your emotions and that it is very difficult for you to control.”

Patricia

- **Distract yourself**
Some people say this helps them when they feel themselves starting to get emotional. So get up and go to another room or ask if you can change the topic of conversation or the TV channel. If you're out with other people, ask someone else to distract you or recite something over in your head – whatever works best for you.

What can I do about feeling frustrated or angry?

- **Let it out**
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 steam. Relaxation can also help you to release tension and calm down. Simple things like pounding a pillow or allowing yourself to have a good cry can get it all out too.
- **Listen to others**
Talk to your friends and family to work out what 'triggers' your anger (is it when you're tired or bored for example?) and what you can do to avoid it. Agree a prompt that they can use to let you know that you're becoming angry or aggressive. It can be as simple as a word or a gesture, just something that will prompt you to take a step back and calm down.

We have more information and advice about managing aggressive behaviour in our booklet *Changes to your behaviour*. Visit stroke.org.uk/publications to find it.

Where can I get help and support?

If you're concerned about any changes to your emotions, 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 meet with you and your family and give you 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**
- write to us at Stroke Information Service, Life After Stroke Centre, Church Lane, Bromsgrove, Worcestershire B61 8RA.

Other organisations that can help

Below are some other organisations in the UK that may be able to help. Contact our Stroke Helpline if you'd like to know about others in your area.

The following **mental health charities** can provide information, advice and support about emotional problems.

MIND/ MIND Cymru (England and Wales)
Website: www.mind.org.uk
Infoline: 0300 123 3393
(Monday-Friday, 9am-6pm)
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



The following **NHS websites** can tell you more about specific emotional problems. NHS Choices has a 'moodzone' and NHS Inform has a 'mental health zone', which have tips to help you cope with anxiety and depression, as well as information about good mental health.

NHS Choices

(England, Wales, Northern Ireland)

Website: www.nhs.uk

Moodzone: www.nhs.uk/moodzone

NHS Inform (Scotland)

Website: www.nhsinform.co.uk

Mental health zone:

www.nhsinform.co.uk/mentalhealth

If you'd like to know what **counselling or talking therapy services** are available in your area, you can look them up using the following websites:

NHS Choices (England)

Website: [www.nhs.uk/Service-Search/Counselling-NHS-\(IAPT\)-services/LocationSearch/396](http://www.nhs.uk/Service-Search/Counselling-NHS-(IAPT)-services/LocationSearch/396)

NI Direct (Northern Ireland)

Website: www.nidirect.gov.uk/index/do-it-online/health-and-well-being-online/find-health-services-in-your-area.htm

Click on your local trust and follow the link to its website, where you can search for mental health services.

NHS Inform (Scotland)

Website: www.nhsinform.co.uk/Support-Services/Topic?letter=C&topic=Counselling%20-%20for%20general%20problems

NHS Direct (Wales)

Website: www.nhsdirect.wales.nhs.uk/localservices/searchlocalservices.aspx
Click on 'Health, Wellbeing & Support' and choose from the topics in the drop down menu.

The **British Association for Counselling and Psychotherapy** can tell you about private talking therapy and help you find a qualified therapist.

Website: www.itsgoodtotalk.org.uk

Tel: 01455 88 33 00

(Monday–Friday, 8.45am–5pm)

Email: bacp@bacp.co.uk

Samaritans offer confidential, non-judgemental emotional support over the phone. They are open 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 tough. 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 for them

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 you have someone to talk to too.

"Neil's still not the man I married but he's slowly coming back; he's becoming 'him' again."

Ann

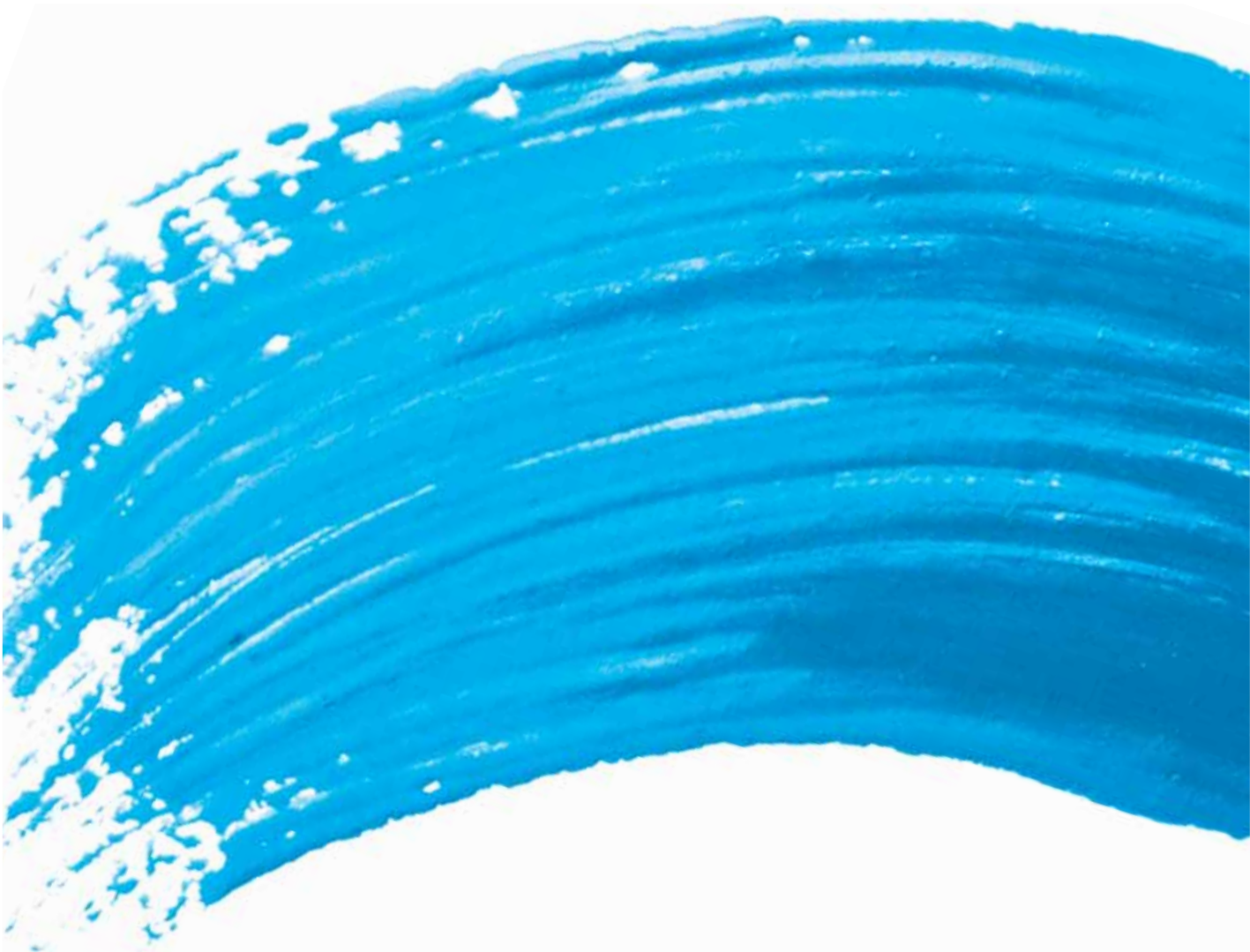
About our information

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.

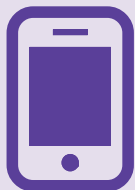
We're here for you. If you'd like to know more, please get in touch.

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.

Together we can conquer stroke

© Stroke Association 2015

Version 1

Published: April 2015

Next review: April 2018.

Item code: **A01F10CG**

