

Emotional changes after a **stroke**

A guide to supporting your group
members and volunteers

stroke.org.uk

Rebuilding lives after stroke

Stroke
Association



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About this guide

This guide provides information and advice on how you can support your group members with the emotional changes they may feel after a stroke.

Everyone’s experience of stroke is unique, 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 in their own way. It’s not always easy to talk about our emotions – particularly if a stroke has caused communication difficulties. But, with the right help and support, people can and do feel better.

Stroke groups offer vital support that can improve a stroke survivor’s quality of life. They provide a space to learn new skills, socialise with other people affected by stroke, and regain confidence. This can help to stop people from becoming isolated.

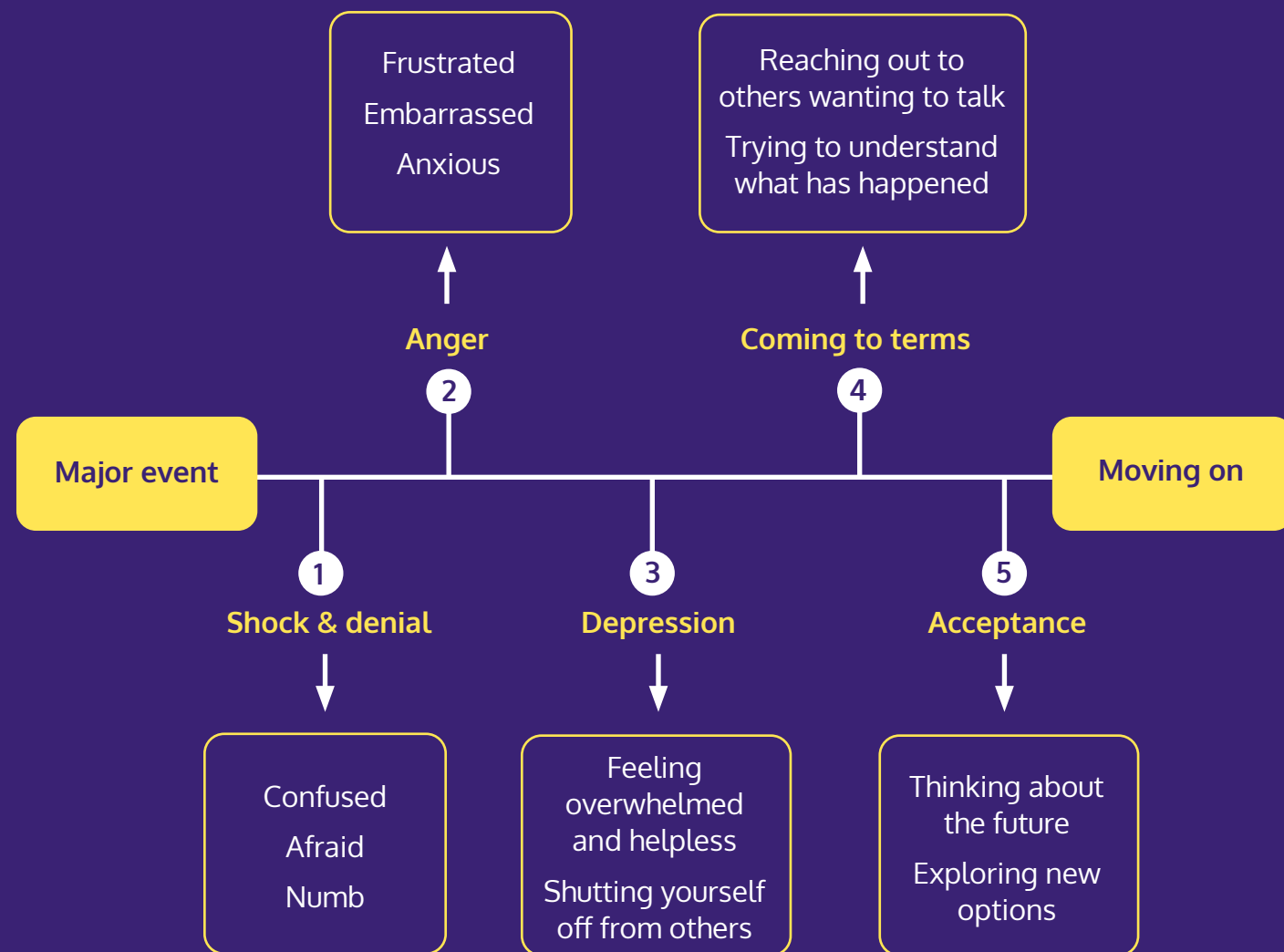




Coping with change

A stroke is sudden and shocking. It can affect every part of someone's life, including their emotional wellbeing.

Not only is the stroke survivor going through all these emotions themselves but the people around them might be, too. Often, people don't want to admit how they're feeling and put on a brave face. So others may not realise what they're going through. Communication problems may mean that some stroke survivors can't explain how they're feeling, even if they want to.



Everyone is different and will move through each of these stages at a different pace. Some people may need help and support to move forward to the next stage.



Signs someone is struggling with their feelings

It's not always easy to know how someone is feeling. Many people try to hide their feelings, putting on a 'brave face', while others show obvious signs of distress.

Here are some things to look out for:

Depression

Signs of depression include:

- Losing confidence.
- Losing interest in activities.
- Lack of energy and motivation.
- Avoiding socializing.
- Difficulty concentrating and making decisions.
- Difficulty holding conversations.
- Sleep problems.
- Loss of appetite or eating too much.
- Self-loathing.
- Negative thoughts.
- Anger or irritability.

Anxiety

Signs of anxiety include:

- Acting restless and on edge.
- Difficulty concentrating.
- Trembling or shaking.
- Shortness of breath.
- Urgently needing the toilet on a regular basis.
- Tiredness.
- Avoiding situations that were enjoyable before.
- Sleep problems.
- Irritability.

Difficulty controlling emotions (emotionalism)

Signs of emotionalism include:

- Crying or laughing for no reason.
- Expressing more intense emotions than usual.
- Small things setting off a bigger reaction than expected.
- Expressing emotions that seem out of place or come and go very quickly.



If you suspect a member of your group may be having difficulties, don't ignore it.

It doesn't matter if you're wrong, it's always better to check.



Supporting your group members

Many people find it helpful to talk to others who have been through a similar experience. **Here are some tips for having a supportive conversation with a stroke survivor:**

Find a quiet spot where you won't be interrupted. Make sure the person is comfortable and has everything they need – this will help them feel relaxed.

Give them plenty of time and space to express how they're feeling.

Listen actively. This means giving someone your full attention and providing 'verbal' and 'non-verbal' feedback. Verbal feedback includes things like asking questions and making sure you've understood what someone has said by repeating it back to them. Non-verbal feedback includes nodding and making eye-contact.

Put yourself in their shoes. Some group members may share very personal feelings. Try to understand their situation and empathise with how they may be feeling.

Be accepting and non-judgemental. Try to remain neutral and avoid making assumptions or judgements.

'Normalise' their feelings. Make them aware that how they are feeling is perfectly normal for someone who has experienced a stroke.

Avoid giving advice. Some group members may ask for your opinion. Instead of giving advice, tell people about the professional advice and support that's available (**see page 8**).



How to respect boundaries and confidentiality

As a volunteer, you provide essential support that makes a huge difference to stroke survivors. However, it's important to remember the limits for your own wellbeing. It's also important to respect confidentiality and take extra care to keep your group members and their information safe.

Boundaries

- Be clear on what you're comfortable to share with others, and what you're happy for them to share with you.
- Be vocal about the boundaries you're setting for yourself and others.
- Avoid doing things that may lead to someone becoming too dependent on you.
- Don't get personally involved with the financial affairs of a group member.
- Be careful about any personal details you reveal about yourself and others.

Confidentiality

All personal information should be treated as confidential. This includes:

- Contact details.
- Details about their personal circumstances or their sexuality.
- Information about their stroke.
- Details of their family and friends.



Don't share this information unless the person explicitly gives you permission to do so as a part of your volunteering your role.



The only exception to this rule is if you learn something that causes you concern. If you're worried about a group member's health or their safety, let your line manager or a Stroke Association staff member know immediately.



How you can help in difficult situations

What to do if you're concerned about someone's safety (safeguarding)

Sometimes, it can be hard to know what to do if you're concerned about a group member's welfare. For example, you've noticed someone who is usually well presented has looked messy or untidy the last few times you've seen them, or a usually cheerful member of the group has become quite withdrawn.

If you feel concerned and would like to take action to help someone, here are some steps you can follow:



Recognise

If something doesn't seem right, let your Stroke Association contact know. Even if it's just a feeling and you're not sure about what is wrong.



Record

Write all of your concerns in an email to your local staff member. Include the date, time and your thoughts as to why something may be wrong. Don't list any personal data that could identify the person in the email. Just use their initials at this stage.



Report

Within 24 hours, speak to your local staff member on the telephone to discuss your concerns. Tell them the full details of the person or people involved. If they're not available, phone your local Stroke Association office and report your concerns to a staff member who can help you.

It's good to keep in mind that there might be a logical explanation to the changes you've seen in someone. For example, the person who is looking a bit untidy may not be able to see very well in the morning because their eyesight is deteriorating. And, the person who has become withdrawn may be dealing with a personal or family issue and is finding it hard to remain cheerful.

But, it's best to report any concerns to a staff member so that they can look into the situation.

We provide free training that will help you understand more about what to do if you have concerns that somebody is being abused or neglected.

Talk to your local staff contact about booking on to our 'Working with Vulnerable Adults' training course.

Do's



Support and reassure



Give attention and time



Give information



Listen to their needs



Signposts where relevant

Don'ts



Do nothing



Be embarrassed



Tell them not to cry



Minimise their feelings



Ignore or leave them alone.



What to do if a group member tells you they are having suicidal thoughts

If someone is experiencing suicidal thoughts and feelings, they may be considering taking their own life. They are likely to be scared or confused and may reach out to you.

Here are some ways you can support them:

- Encourage them to talk about their feelings. There's no right or wrong way to talk about suicidal feelings – starting the conversation is what's important.
- Allow them the time and space to get through what they want to say.
- Let them know they're not alone and that people care about them.
- Try and encourage them to get help and explore the options available to them:
 - Anyone can call the Samaritans on **116 123**.
 - CALM (Campaign Against Living Miserably) is specifically for men who need to talk. Call **0800 58 58 58**.
 - The Silver Line is a helpline for older people. Call **0800 470 80 90**.
 - Papyrus is for people who are under 35. Call **07786 209697**.
 - Childline is for children and young people under 19. Call **0800 11 11**.
 - Make an appointment with their local GP.
 - Call 111 out of hours – they will help them find support.

If you think that someone is in urgent danger and is going to try to take their life, or has already tried, **call 999**.



Where else to go for help

If you think a group member would benefit from some extra help or from talking to a professional, encourage them to get this support as soon as possible. You can help them by finding out what options are available and talking through them together.

Here are some examples of the help and support available to them:

Current support systems

This includes family, friends, carers, neighbours and health and social care workers.

Their local GP

Encourage them to make an appointment or emergency appointment/out of hours service.

Emergency services

If they find themselves in crisis, they can call 999 or go to A&E.

Helplines

Samaritans:

Telephone: 0845 909090 or 116 123 (24 hour)
[samaritans.org](https://www.samaritans.org)

Rethink:

Telephone: 0300 5000 927 (10am – 2pm)
[rethink.org](https://www.rethink.org)

Stroke Association:

Telephone: 0303 303 3100 (9am - 5pm)
stroke.org.uk/helpline

Mind:

Telephone: 0300 123 3393 or 116 123
(9am – 6pm)
[mind.org.uk](https://www.mind.org.uk)

Sane:

Telephone: 0300 304 7000 (6pm – 11pm)
[sane.org.uk](https://www.sane.org.uk)



Online forums

Rethink, Sane, Mind, the Mental Health Foundation and Depression Alliance all have online forums. You'll find links on their websites.



Counselling

This can be arranged through their GP or a private counsellor. Visit [bacp.co.uk](https://www.bacp.co.uk) for more information about private counsellors.

You can also signpost people to resources on our website stroke.org.uk/resources.



Training

You can also learn more about the emotional impact of stroke by going on our Emotional Impact of Stroke course.



Other useful resources

- A complete guide to emotional changes after a stroke
- Depression and other emotion changes

You can download these guides or order a printed copy from our online shop at stroke.org.uk/shop/product/depression-and-other-emotional-changes-guide

Your stroke group can provide a safe and welcoming environment so that all members feel comfortable to share how they are feeling and ask for help.

If you have any questions or would like more advice, please call our Volunteering and Community Partnerships Team on **0207 566 1540** or email clubtogether@stroke.org.uk.

When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at **stroke.org.uk**

Contact Us

Stroke Helpline: **0303 3033 100**

From a textphone: **18001 03033 100**

Email: **helpline@stroke.org.uk**

Website: **stroke.org.uk**

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