



# The hidden effects of stroke

## A guide for group volunteers

Rebuilding lives after stroke

**Stroke**  
Association

There are lots of different ways a stroke can affect someone. There are things you can see and hear, like weakness in the arms or face and slurred speech. But, there are also things that are 'hidden', like problems with emotions and the senses.

This factsheet will help volunteers at stroke groups to spot the hidden effects of stroke and support someone who is experiencing them.

### How a stroke support group can help

Our stroke groups pride themselves on understanding their members and always putting their needs first. That's why our volunteers need to be aware of all the effects of stroke, including the hidden ones, so they can offer help and support.

Remember, each stroke is different. Every person is different. So the effects of stroke, and the impact they have on someone's life, will vary from person to person. Here are some of the main effects of stroke:

### Effects of stroke you can see and hear

- Movement and balance
- Continence problems
- Behaviour changes
- Problems noticing things to one side (also known as spatial neglect)
- Swallowing problems (dysphagia)
- Communication difficulties like aphasia
- Weak face muscles
- Problems with concentration and memory

# Effects of stroke that are hidden

## Fatigue

Fatigue, or tiredness that doesn't get better with rest, can remain for months or years after a stroke. Because the person may look well, it can be hard to accept that they are struggling with fatigue. It's common after a stroke, and can be a serious problem for some.

## Emotional effects

Stroke is closely linked to emotional problems like low mood, depression and anxiety. Some people experience emotionalism, which means they find it hard to control their emotional responses like laughing and crying.

## Memory and thinking

Problems with memory and concentration – also known as cognitive problems – are very common after a stroke. Stroke survivors often feel confused at first, but for many people this improves after a few after a few weeks.

## Vision

About 60% of people have vision problems after a stroke. Problems can include double vision or being very sensitive to light. Some people lose part of the visual field, which means not being able to see everything you're looking at.

## Pain

Some people experience long-term pain such as burning sensations or muscle and joint pain.

# How to spot the hidden effects of stroke

Members of your group might have one or more of these hidden effects. The rest of the group may not know about them. They could also be hidden from carers, family, friends and even health professionals.

Your group is a place where people affected by stroke should feel safe and comfortable to talk about any issues affecting their health and wellbeing.

Volunteers should encourage members to discuss any difficulties they are having, so the group can give them the support they need.

## How can you find out if your group member is having difficulties?

- Your group member may tell you in a private conversation or when completing their membership form.
- A carer, family member or friend may tell you.
- You may spot the difficulties yourself.

## How can you support your group member?

Here are three examples to help you to:

- Spot the hidden effects of stroke
- Recognise the impact they may be having on someone's life
- Work out the best way to support them.

## Example 1

Volunteer Judy has noticed that two members of her group are struggling to join in conversations and activities.

### Action

At the Annual Review Meeting, Judy asks group members to give feedback on how the group is going. She also has private conversations with group members. She finds out that a group member is having difficulties. Carol has trouble concentrating. She also gets tired quickly, especially if there's a lot of noise in the room.

### Response

To help Carol, Judy splits the group into smaller groups for activities. Sometimes they go into different rooms. This keeps the noise down.

## Example 2

Mark runs a stroke group. He notices a group member, Lewis, is always very quiet and doesn't join in activities.

### Action

Mark has a private conversation with Lewis. He asks him how he's getting on in the group. Is there anything he's finding difficult? Is there anything he needs support with? Mark finds out that Lewis has been having problems with his speech since his stroke. It's affected his confidence.

### Response

Mark suggests that Lewis goes back to the GP or stroke team and ask for an assessment of his communication needs. Mark orders a Communication Toolkit from the Stroke Association. This helps him to create activities and materials that Lewis finds easier to understand and follow. He also shares information about aphasia with the group. This will help them understand how to communicate with Lewis. Mark gives Lewis contact details for a local communication support service.

## Example 3

Simon runs a stroke support group and is worried about group member, Annette, who has been feeling low for a long time.

### Action

Simon looks on the Stroke Association website to learn a bit more about depression after stroke. During an informal discussion with Annette, Simon mentions that Annette has been a bit quiet recently and asks if everything is OK. Annette then explains how down and isolated she's been feeling since her stroke.

### Response

Simon listens carefully to Annette and reassures her that these feelings are common after such a big change. He then provides information on depression from the Stroke Association and signposts Annette to some useful sources of support such as her local GP, online forums and the Stroke Helpline. Simon later follows up to check that Annette has sought help and is feeling less alone.

## More information

For more materials for your group, visit [stroke.org.uk/resources](https://stroke.org.uk/resources).

You might find these resources useful:

- Supporting a stroke survivor
- Next steps after stroke

To find a Stroke Association service near you, or if you need any support, please call our Helpline on [0303 3033 300](tel:03033033300).

To find out more about groups in your area visit:  
[stroke.org.uk/finding-support/support-groups](https://stroke.org.uk/finding-support/support-groups)

## Contact Us

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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](https://stroke.org.uk)

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