

Rare effects of stroke

This guide explains some of the rare effects of stroke, how you can cope with them and the treatments that are available to help. We also list some organisations that can offer further information and support.

Rare effects of stroke

A stroke can affect any part of your body because it happens in the brain, which controls everything you do. Although no two people are the same, many experience similar difficulties, such as weakness on one side of the body, or problems with walking or communicating. However, some people experience more unusual effects of stroke. These may be hard to understand and cope with, as not many people are affected in the same way.

This guide describes the following rare effects of stroke:

- hallucinations and delusions
- taste and smell changes
- locked-in syndrome.

Hallucinations and delusions

After a stroke, a small proportion of people can develop psychotic symptoms including visual or auditory hallucinations and delusions. These effects depend on where in the brain the stroke took place, and they can also be linked to other health conditions including infections, seizures

and dementia. Symptoms can also be linked to medication or mental health problems such as depression or bipolar disorder.

Hallucinations

A hallucination is when someone sees or hears something that isn't there. There are many different types of hallucinations. You may see people or objects that no-one else can see (visual hallucinations), or hear sounds, like someone talking, when no-one is around (auditory hallucinations). In rare cases, people may smell, taste or feel things that are not there.

Peduncular hallucinosis

This is a type of visual hallucination that can occur when there is damage to a part of the brain called the midbrain. These hallucinations often involve vivid, colourful scenes with animals, people and patterns. The visual hallucinations may disappear within a few weeks, but they may carry on for a longer period. Each hallucination may last for several minutes or up to several hours, and they often occur in the evening. Many people don't find the hallucinations worrying and realise they are not real.

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Charles Bonnet syndrome

Visual hallucinations are quite common after a sudden loss of vision, which can happen after stroke. This is called Charles Bonnet syndrome. These types of hallucinations are usually temporary but may last for several months before reducing. The hallucinations can appear as simple patterns or complex images of people, places and objects.

What treatment is available?

Hearing sounds or seeing things that are not there can be upsetting and frightening. Having a proper diagnosis and understanding what is happening can be reassuring and can help you to cope with them.

Hallucinations usually become less intense over time, and treatment depends on the cause. Charles Bonnet syndrome can't be cured, but a person may be helped by treatment for their vision problems. Medication can help some people, and reassurance or self-help strategies can assist a person living with the condition. Hallucinations due to other causes may be treatable by medication, psychological support or treating an underlying infection. Talk to your GP, who may be able to refer you to a mental health specialist such as a psychologist or counsellor. The Royal National Institute of Blind People (RNIB) has information about coping with hallucinations, which may be helpful (see *Where to get help and information* later in this guide).

Delusions

Delusions are strong beliefs about something that is untrue. For example, some people feel that someone is spying on them, or that they are in danger when they are really safe.

Capgras syndrome is a specific type of delusion that makes a person feel like someone they know has been replaced by an imposter, such as an alien or a double who looks like them. In some cases people have been known to also relate this to themselves. For example, when looking at an old photograph of themselves, they don't feel like it is them or they might refer to themselves in the third person.

What treatment is available?

For most people, delusions become less of a problem over time. If the symptoms are mild, no treatment is usually necessary. If the effects are significant or disruptive, then you may need treatment for depression and anxiety, or rarely with antipsychotic medication. Treatment for Capgras syndrome can also include psychotherapy or counselling. Talk to your consultant or GP about what treatment would be best for you.

Taste and smell changes

Your sense of taste and smell are very closely linked (smell helps to define your sense of taste). Often when people lose their sense of taste and visit the doctor, they learn that what they are suffering from is actually a smell disorder.

Taste changes

Many things can affect your sense of taste such as taking some types of medication or smoking. However, it can also be affected by damage to the brain caused by a stroke. There are different types of problems with taste.

- Hypogeusia – a reduced ability to taste. You will not be able to taste all flavours such as sweet, savoury or bitter as well as before.

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- **Dysgeusia** – a distortion of taste. If you are suffering from dysgeusia, it can leave you with a salty, foul or metallic sensation in your mouth. Along with distorted taste, people with dysgeusia can sometimes experience a painful burning sensation in the mouth.
- **Ageusia** – a loss of taste. This means you cannot detect any tastes at all.

Oral hygiene

Poor oral hygiene can also contribute to changes in your sense of taste. It is important to maintain good oral health by looking after your mouth, teeth and gums to make sure your mouth does not become dry or sore. Swallowing problems, as well as other effects of stroke such as paralysis or weakness may make this difficult. Some types of medication can also add to these difficulties by giving you a dry mouth or affecting the control of your saliva. Saliva is essential for our sense of taste.

If you are not able to swallow, you or your carer should regularly take steps to maintain good oral health. This includes brushing your teeth, cleaning your gums and cleaning any dentures. You may need to keep your mouth moist by using wet swabs and putting some petroleum jelly around your lips.

Smell disorders

Your ability to smell can be affected by damage to the area of the brain that controls your sense of smell. There are different types of smell problems:

- **hyposmia** – a reduced ability to smell
- **anosmia** – loss of smell

- **hyperosmia** – oversensitivity to smell
- **dysosmia** – a distorted sense of smell.

What treatment is available?

Problems with taste and smell can be very frustrating as you may not be able to enjoy eating and drinking as you did before your stroke. This can lead to weight loss or malnutrition, so it's important to ask your GP for help if you are having trouble eating enough to stay a healthy weight. In addition, if you cannot smell properly, you may be unable to recognise warning smells such as harmful gases or smoke.

There are various tests you can have to find out whether you have smell or taste problems. Taste can be tested by using foods that are from the different taste qualities, such as sugar, lemon juice and salt. Your doctor may check your mouth for dryness or infection. It is important to have regular check-ups with your dentist.

To test your sense of smell, doctors may ask you to smell common fragrant substances such as coffee, cloves or soap, using one nostril at a time. You will then be asked to try and identify what the smell is. Your GP may then refer you to see an otolaryngologist (a specialist for problems with ears, nose and throat) who will try to assess what the problem is, and can advise on whether there are any treatments that could help.

Talk to your doctor if you are experiencing changes in your sense of taste and smell. They can check if it's a side-effect of the medication you are taking, and they can refer you to a dietitian for further advice and support. Many people's sense of taste and smell improves in time.

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Helpful tips for taste problems

If you experience changes to your sense of taste, there are some things you can try to make your food taste better. Some people add more salt or sugar to boost flavour, but it's a good idea to avoid this as it can lead to high blood pressure or weight gain. Check with your doctor before trying foods that you don't usually eat, particularly if you have diabetes or are taking medications such as warfarin.

- Try eating food cold or at room temperature, rather than hot. Sometimes, cooling can reduce strong or sweet flavours.
- Drink plenty of fluids to remove any unpleasant tastes in your mouth. Try squashes, fruit juices, tea, coffee or water.
- Dilute sweet beverages or juice with water, soda or tonic water.
- Chewing sweets such as mints or boiled sweets can help to refresh your mouth. Try sugar-free varieties.
- Keep your mouth clean and brush your teeth regularly and thoroughly, including brushing your tongue.

Ideas to flavour food

- Use aromatic herbs and spices, which will add more flavour. Try herbs like tarragon, rosemary and mint, or spices like cloves and cinnamon.
- Prepare and make foods with a variety of textures and colours to add to visual appeal.
- You could try adding toasted nuts or olive oil to vegetables to add flavour.

- Avoid eating dishes that are a combination of foods, such as casseroles as they can dilute and hide the individual flavours.
- Add chilli, spices or curry powder to savoury dishes.
- Use pickles, bottled sauces or salsa. Adding lemon and lime juices or Worcestershire sauce to cooking adds flavour.
- Olives, garlic or pesto may add flavour to pasta dishes.

If food tastes too sweet

- Choose sharp-tasting fruits such as gooseberries, blackcurrants, grapefruit or stewed rhubarb in pies or tarts.
- Add spices to puddings, for example, nutmeg to rice pudding or custard, or ginger to stewed fruit or fresh melon.

If food tastes bitter

- Sweet flavours such as honey, jam, or sweet spices like cinnamon may hide bitter tastes. Artificial sweeteners may also help. If you have diabetes, check with your GP first.
- If tea or coffee tastes bitter, try alternatives, such as lemon or herbal tea, cocoa, hot chocolate or fruit juices.
- Don't use salt to enhance flavour in food. Too much salt can raise your blood pressure, which is a major risk factor for stroke.

Locked-in syndrome

Locked-in syndrome is a rare condition where someone is completely paralysed in all parts of their body, apart from the muscles that control eye movement. It can happen because of a number of different conditions such as traumatic brain injury, diseases of the circulatory system and stroke.

If locked-in syndrome is caused by a stroke, it is usually due to a stroke that has happened in the part of the brain called the brain stem. The brain stem is the area at the top of the spinal cord at the junction between the spinal cord and the two halves of the brain (the left and right hemispheres). Every nerve that travels between the spinal cord and the brain must travel through the brain stem. This area controls and regulates many automatic body functions, such as breathing, pulse rate, blood pressure and the digestive system. It also contains nerves that control the face, head, eye movement and balance.

People with locked-in syndrome are conscious and can think and reason, but are unable to speak or move. Some people with locked-in syndrome can communicate with others through blinking or eye movements.

Different types of locked-in syndrome

- Classic locked-in syndrome – when someone is conscious and paralysed apart from vertical eye movements.
- Incomplete locked-in syndrome – when someone has some other small areas of movement as well as eye movement.

- total locked-in syndrome – when someone has complete paralysis (including the eyes) so they are unable to communicate at all but are fully conscious.

What treatments are available?

Diagnosing locked-in syndrome can be difficult, as someone may be in a coma following a stroke and then emerge from it into a locked-in state. Often the diagnosis of locked-in syndrome happens because a family member or care staff notice small signs of awareness.

There is no specific treatment or cure for locked-in syndrome. Initial treatment should involve maintaining the person's airway so they are able to breathe. Treatment should also aim to prevent any further complications which could happen because they are not able to move or swallow. For example, care should be provided to ensure the person is comfortable, that they do not develop bed sores and to stop their muscles tightening. Chest physiotherapy and moving the person frequently can help to reduce any complications with the lungs such as infections.

If someone is unable to close their eyes properly, they may develop ulcers on the part of the eye called the cornea, which may need treatment.

Although most people remain in a constant locked-in state or are left severely disabled, some people may show early signs of recovery. If this happens it is important they have access to specialist rehabilitation services. This means a range of professionals such as physiotherapists and speech and language therapists will be working together to support the person

to make the best recovery possible for them. Rehabilitation may focus on any small voluntary movements that are available such as finger movement, swallowing and making sounds.

Communicating with someone with locked-in syndrome

A speech and language therapist may be involved to help the person affected by stroke to establish a code using eye movements or blinking to communicate. It is important for others to use effective questioning skills – for example, avoiding open-ended questions and confirming answers by repeating questions where necessary.

There are some types of assistive technology that can help someone with locked-in syndrome to communicate. These can range from simple alphabet boards to more sophisticated electronic aids.

What is the outlook?

For many people with locked-in syndrome, the severe effects of their stroke remain. However, therapy and careful planning can help to improve someone's quality of life and may even enable them to return home to live with the support of their family.

Many years ago the survival rate for people with locked-in syndrome was very low. However, earlier rehabilitation and better nursing care has led to better survival rates. Although it is extremely rare for someone to recover from locked-in syndrome, there are some books and personal accounts by survivors (see *Other sources of help and information*).

Where to get help and information

From the Stroke Association

Talk to us

Our Stroke Helpline is for anyone affected by a stroke, including family, friends and carers. The Helpline can give you information and support on any aspect of stroke.

Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100** or email info@stroke.org.uk.

Read our publications

We publish detailed information about a wide range of stroke topics including reducing your risk of a stroke and rehabilitation. Read online at stroke.org.uk or call the Helpline to ask for printed copies.

Other sources of help and information

Orphanet

Website: www.orpha.net

A searchable database of rare diseases. Includes useful information about each disease and any related research projects.

Locked-in syndrome

Royal Hospital for Neuro-disability

Website: www.rhn.org.uk

Tel: 020 8780 4500

A charity that provides assessments, rehabilitation and care for people with brain damage or brain disease. They also have a variety of assistive technologies that help people with locked-in syndrome to communicate.

Personal accounts of locked-in syndrome

Clodagh Dunlop

Facebook page:

www.facebook.com/clodaghbeatinglockedin

Clodagh Dunlop had a brain-stem stroke in 2015 and had locked-in syndrome for three months before starting to recover. She returned to work in 2016. She writes about locked-in syndrome and stroke on her Facebook page.

Manuel Longo

Website: www.mlongo.net

The website of Manuel Longo, a man from Malta who had an ischaemic stroke in 2000 and has locked-in syndrome.

Books

The diving bell and the butterfly

Jean-Dominique Bauby

1997, *Fourth Estate*

Mr Bauby was the editor of the French magazine *Elle*. He had a massive brainstem stroke resulting in locked-in syndrome. He dictated this book by blinking his eye in response to assistants reading out the letters of the alphabet. His story was released as an award-winning film in 2007.

In the blink of an eye

Hasso and Catherine von Bredow

2009, *Orion Publishing*

Hasso von Bredow (a father of three and successful businessman) had a brainstem stroke, leaving him with locked-in syndrome. He used coded blinking and state-of-the-art technology to write this moving and life-affirming memoir, helped only by his wife.

Hallucinations and delusions

Royal National Institute of Blind People (RNIB)

Website: www.rnib.org.uk

Tel: 0303 123 9999

Email: helpline@rnib.org.uk

Information and support for people with visual problems. Has useful information about coping with hallucinations.

Taste and smell changes

British Dietetic Association

Tel: 0121 200 8080

Website: www.bda.uk.com

Provides information on various aspects of diet and nutrition.

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.

Accessible formats

Visit our website if you need this information in audio, large print or braille.

Always get individual advice

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Together we can conquer stroke.

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