

## Rare effects of stroke

A stroke can affect you in many different ways. Some effects of stroke are common, like having weakness on one side of your body or problems with your vision, but others are rare. This factsheet 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.

A stroke can affect any part of your body because it happens in the brain, which controls everything you do. Although no two strokes are the same, many people experience similar difficulties, such as 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 factsheet describes the following rare effects of stroke:

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

### 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 has to 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 are able to communicate with others through blinking eye movements.

There are different types of locked-in syndrome:

- **classic locked-in syndrome** – when someone is conscious and paralysed apart from vertical eye movements

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- **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.

Some people may experience temporary locked-in syndrome. The symptoms only last a few minutes and they usually make a good recovery.

### What treatments are available?

Diagnosing locked-in syndrome can be difficult, as someone may be left 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 have noticed 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.

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 ensure they have the best chances of recovery.

### 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. For more information, see our resource sheet *R5, Communication aids and computer therapy after stroke*.

### What is the outlook?

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

Many years ago the survival rate for people with locked-in syndrome was very low. More recently, it is thought that earlier

rehabilitation and better nursing care has led to **better survival rates**. Some studies have shown that survival rates after 10 years can be as high as 80 per cent. Studies have also shown that, contrary to what many people think, people with locked-in syndrome can have a quality of life.

There have been cases where people have recovered from locked-in syndrome. See the *Useful organisations* section for details of inspiring stories from some survivors of this condition.

### Hallucinations and delusions

Hallucinations and delusions are conditions that someone may experience if they have psychosis. Psychosis is a type of mental health issue that seriously **affects the way a person thinks or feels**. Sometimes they can **lose touch with what is real**. Psychosis is rare after stroke and affects about one per cent of people. If you are suffering from psychosis you may be unaware that anything is wrong and will genuinely believe that what you are feeling is real and is happening.

#### 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 (called visual hallucinations), or hear sounds, like someone talking, when no one is around (called 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 usually start within a few days of the stroke happening and may disappear within a few weeks – however they may last for years. Each hallucination may last for several minutes or up to several hours, and they often occur in the evening. Many people eventually develop an insight into their hallucinations, realising they are not real, and may find them interesting.

**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. Many people experience them for 12 to 18 months before they become much less frequent.

The sorts of things you may see can vary. The hallucinations may be in colour or in black and white. They may fit in with the background you are looking at, for example seeing animals in a field, which is really empty, or they may be totally unreal, for example some people see fantasy scenes.

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.**

#### What treatment is available?

**Hallucinations usually become less intense over time**. Sometimes talking about your hallucinations and how you feel can help you to cope with them. If you are finding them

very upsetting, talk to your GP, who may be able to refer you to a mental health specialist such as a psychologist or counsellor. The RNIB have information about coping with hallucinations, which may be helpful (see *Useful organisations* for their contact details).

### 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 as 'the other' 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 be treated with **antipsychotic medication** such as clozapine, pimozide or riseridone.

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 actually they are suffering from a smell disorder instead.

### 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 flavours such as sweet, savoury or bitter as well as before.
- **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. It means that you cannot detect any tastes at all, but this is very rare.

### 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

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weakness, may make this difficult. Some types of medication can also add to 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, ideally every four hours, 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

Smell can be disrupted by many things such as a virus. In rare cases, 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.

Although these problems with taste and smell are not life-threatening, they can be very frustrating as you may not be able to enjoy eating and drinking as you did before your stroke. More seriously, if you cannot smell properly, you may be unable to recognise potentially harmful gases or chemicals.

### What treatment is available?

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, as well. 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.

### 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. **Check with your doctor** before trying foods that you don't usually eat, particularly if you have diabetes or are taking the medication 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.

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- 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 cooking chicken with tarragon; lamb with rosemary or mint; pork with cloves or apple.
- Prepare and make foods with a variety of textures and colours.
- You could try adding toasted nuts or olive oil on 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 a dash of alcohol (if allowed) to cooking adds flavour.
- Olives, pesto or sun dried tomatoes 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, cinnamon or ginger to stewed fruit or melon.

### If food tastes bitter

- Honey, syrups, jam, marmalade or sugar may hide bitter tastes. Artificial sweeteners may also help, but some can leave an aftertaste in your mouth. 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.

## Useful organisations

All organisations are UK wide unless otherwise stated.

### Stroke Association

**Stroke Helpline:** 0303 3033 100

**Email:** [info@stroke.org.uk](mailto:info@stroke.org.uk)

**Website:** [stroke.org.uk](http://stroke.org.uk)

Contact us for information about stroke, emotional support and details of local services and support groups.

### Locked-in syndrome

#### Royal Hospital for Neuro-disability

**Tel:** 020 8780 4500

**Website:** [www.rhn.org.uk](http://www.rhn.org.uk)

This charity 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.

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### **National Rehabilitation Information Center**

**Website:** [www.naric.com](http://www.naric.com)

An American website through which you can access research studies into recovery and long-term outcomes for people affected by locked in syndrome.

### **ALIS – Association du Locked-in Syndrome**

**Website:** [www.alis-asso.fr](http://www.alis-asso.fr)

A French website about locked-in syndrome. Depending on the web browser you use, you may be able to view an English version of this website.

### **Fighting strokes**

**Answerphone helpline:** 0114 236 9222

**Website:** [www.fightingstrokes.org](http://www.fightingstrokes.org)

A charity that aims to inspire people with locked-in syndrome, particularly young people.

### **Stroke support group**

**Website:** [www.strokesupportgroup.org/forums/forum/109-locked-in-syndrome](http://www.strokesupportgroup.org/forums/forum/109-locked-in-syndrome)

Online support group, including a forum for people affected by locked-in syndrome.

### **Locked-in syndrome website**

**Website:** [www.mlongo.net/home.php](http://www.mlongo.net/home.php)

A website from someone with locked-in syndrome in Malta.

### **Books**

#### **The diving bell and the butterfly**

Jean-Dominique Bauby

Paperback 1997 Fourth Estate, London.

Mr Bauby was the editor of the French magazine *Elle*. He had a massive brain stem 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  
Hardback 2009 Orion Publishing.

Hasso von Bredow (a father of three and successful businessman) suffered a massive 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**

#### **RNIB**

**Tel:** 0303 123 9999

**Website:** [www.rnib.org.uk](http://www.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](http://www.bda.uk.com)

Provide factsheets on various aspects of diet and nutrition.

**Disclaimer:** The Stroke Association provides the details of other organisations for information only. Inclusion in this factsheet does not constitute a recommendation or endorsement.

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For sources used, visit [stroke.org.uk](http://stroke.org.uk)

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