

When someone is seriously ill or dying after a stroke

Stroke Helpline: 0303 3033 100
or email: helpline@stroke.org.uk

This guide is for the family and friends of someone who is seriously unwell after a stroke. As well as medical questions, we also cover some of the things you may need to know about making decisions on someone else's behalf.

People can and do survive strokes that damage large areas or vital parts of the brain. But any serious stroke is more likely to lead to someone becoming very unwell, or their life being at risk. The medical team should help you to understand what is happening and what treatment they are giving.

With rapid medical help, many people can survive an initial stroke. Good treatment and care allows people to make the best recovery possible for them. But even with good care, a severe stroke may leave someone with serious disabilities or unable to live independently. Sometimes, a stroke can be severe enough to cause death straight away.

Looking after yourself

When your loved one is so unwell with a stroke that they may not survive, it can be a very difficult and stressful time. This can be even more difficult if the person is unwell for a long period. Often families want to stay with the person who has had a stroke, and hospitals will try to accommodate this. But it is also important to look after yourself. No matter how unwell a loved one is, it is important that you take time to have a meal and get some sleep.

How does a stroke affect the body?

A stroke happens when the blood supply inside the brain is disrupted, killing brain cells. If this happens in a part of the brain that controls the body's automatic 'life support' systems like breathing and heartbeat, it can be life-threatening.

Risk of another stroke

After any stroke, the chance of a second stroke is much higher, and if someone already has damage to the brain, a second stroke can make them much more unwell. The medical team works hard to reduce the risk of a second stroke by treating risk factors like blood clotting, high blood pressure and heart problems.

Swelling in the brain

A serious stroke can lead to dangerous swelling in the brain. This can sometimes be treated with surgery to remove part of the skull and reduce the pressure inside the brain. This surgery is called decompressive hemicraniectomy.

If someone has swelling in the brain, they are often too unwell to make a decision about their own care, so the medical team will work closely with their family or carers to agree the best treatment and care options. While the surgery can save someone's life, it can leave them with very serious disabilities.

Deciding what is best for an individual can be a complex and personal matter for their family and carers, and the medical team will support them in making a shared decision about treatment. See the section '**Making treatment choices on behalf of someone else**' for more information.

A patient decision aid explaining the pros and cons of decompressive hemicraniectomy is available from the National Institute for Clinical Excellence (NICE). See [nice.org.uk/guidance](https://www.nice.org.uk/guidance) for more information.

Complications after stroke

Stroke can lead to serious health complications, which can also cause someone to become very unwell. These can happen soon after a stroke, or many months or years later. The medical team in hospital carry out checks to identify and treat problems as they happen. These can include:

- **Swallowing problems**, which can mean the person inhales particles of food or drink. This can lead to chest infections or pneumonia.
- **Being immobile for long periods**. This increases the risk of deep vein thrombosis (DVT) forming. A blood clot forms in a vein, often in the lower leg. If the clot moves to the lungs, it can block the flow of blood to the lungs, known as a pulmonary embolism.
- **Heart attacks** are more likely after a stroke. They are linked to many of the same risk factors and health problems.
- **Seizures after a stroke**. These have been linked in some studies with greater chance of death and disability.

When someone is unconscious or in a coma

The most severe strokes can leave a person unable to respond or in a sleep-like state. This is sometimes called unconsciousness or coma, and it means that important parts of the brain are not working well. Coma may sometimes mean that the stroke is severe enough that the person may not survive.

Coma can have a number of causes. In some situations, the cause of the coma can be reversed, but often there is no direct treatment. The medical team will support the person's health and see if the coma improves over time. They carry out checks and treatments to reduce the risk of another stroke and avoid complications developing. They also look after the person's comfort and wellbeing.

They will support family members or carers at a difficult time and should let you know what is happening. If you feel uncertain about how you can help, ask the medical team what you can do.

Supporting someone in a coma

Some people who have survived a coma say that they weren't aware of what was happening, but they recognised familiar voices and took comfort from this. So don't be afraid to talk to someone in a coma. When you come in, say who you are and talk to them about your day and other things as you normally would. Remember that they might be able to hear everything said around them.

Physical contact like hand holding can also help, as long as the person would have been comfortable with this when awake. You can try stimulating their senses with music or a favourite perfume.

A person in a coma is not always motionless. They may grasp with their hand or make sounds. This is not always a sign of recovery, and involuntary movement can be seen even in a deep coma.

Different states of consciousness

Doctors assess a person's level of consciousness using a tool called the Glasgow Coma Scale. This allows them to monitor for signs improvement or deterioration. The Glasgow Coma Scale measures:

- **Eye opening** – a score of 1 means no eye opening, and 4 means opens eyes spontaneously.
- **Verbal response to a command** – a score of 1 means no response, and 5 means alert and talking.
- **Voluntary movements in response to a command** – a score of 1 means no response, and 6 means obeys commands.

After a coma, someone might have basic reflexes, like blinking at a loud noise. They may open their eyes and sleep and breathe normally, but show no signs of awareness. This is sometimes called a vegetative state.

If someone has more signs of conscious awareness, like being able to respond to a command or communicate at times, this can be called a minimally conscious state. Some people can continue to gain awareness, but it can be a long-term condition for others.

If you're not sure what state of consciousness someone is in, ask a member of their medical team. They monitor the patient closely, and they can tell you about any changes. They can explain what treatment and support is being given.

If someone can't do things for themselves such as eating and going to the toilet, they may be given help like a feeding tube and a catheter to drain the bladder.

They will be moved to keep limbs flexible and avoid pressure ulcers, and staff carry out basic hygiene like brushing teeth and washing.

They can be given meaningful activities such as listening to music and looking at pictures.

Locked-in syndrome

Very rarely, someone can be conscious but unable to move or speak. This is known as locked-in syndrome. They can usually hear, see, blink and move their eyes. They might be able to communicate by blinking. Locked-in syndrome is often due to a stroke in the brain stem, which is the part of the brain closest to the spinal cord. The brain stem controls vital functions like breathing and heartbeat, as well as consciousness and movement.

Ask the doctor what the person is aware of and what their movements mean, to help you understand their condition. You can find more information at stroke.org.uk about locked-in syndrome.

End of life care

End of life care is support for people who won't recover from an illness. This can last for as long as it's needed and could be days, months or longer. It should help the person live well for as long as they can and die with dignity.

It can include palliative care, which is holistic treatment and support to make someone as comfortable as possible. This can mean managing pain and symptoms, as well as psychological, spiritual and social support for the person and their family.

Where can end of life care be given?

It's possible to have end of life care at home, in a care home, in hospital or a hospice. The choice depends on the advice of the medical team, as well as the wishes of the person and their family. If it's at home or in a care home, the GP is the main point of contact.

Someone in their own home can have care from community palliative care nurses and other specialist professionals. They can also spend time at a hospice, or use the support services offered at a hospice.

Care in a hospital and hospice is free. At home or in a care home, the NHS or local council may fund parts of the care provided. Funding and help available varies between UK countries and local areas. Your GP can help you understand what's available in your area.

Signs that life may be ending

It's not usually possible to predict exactly when someone might die, but there are some signs that show someone is close to the end of their life. In the final days and hours, they may become drowsier, or stop eating and drinking. They can appear confused or restless.

Their breathing can change and become less regular. It may be noisy, due to fluids building up in the airways. This doesn't always cause distress to the person, but can be upsetting for people around them. Health professionals can offer help to relieve symptoms and make the person more comfortable. Some things can help, such as raising their upper body, and medication can be given if needed.

Find out more

There is more information about end of life care on the NHS website at [nhs.uk/conditions/end-of-life-care](https://www.nhs.uk/conditions/end-of-life-care). The websites for the Marie Curie and Hospice UK charities also give information. See the '**Where to get help and information**' section for details.

Making treatment choices on behalf of someone else

Normally patients have to give consent before any treatment, but if someone is unable to respond while they are having a stroke, doctors will give the emergency treatment that's needed.

If someone can't take part in discussions about their own treatment after a serious stroke, or if they are very ill due to complications, other people need to make those decisions.

The exception is when someone has already explained their wish to decline certain treatments. In England and Wales, the 'Advance decision' document (also known as a living will) is legally binding, and in other parts of the UK, it is likely to be treated in a similar way by doctors. Later in this guide, we give more information about advance decisions, and how these can help the family and team caring for someone.

The responsibility for treatment decisions lies with doctors, but they will always try to work closely with family or carers to try to make sure that the choices are made in the best interests of the person needing care. Those around the patient should work together to consider what the person would have wanted, if they are not able to take part in discussions about their treatment.

In some cases, doctors may suggest withdrawing treatment. This will be based on the individual's circumstances, such as how long they have been unconscious, how likely they are to recover, and other health conditions they may have.

Legally, doctors are not able to take active steps to end a person's life. But they can recommend ending active treatments such as antibiotics to treat pneumonia.

This doesn't mean that the person is not being cared for, as the medical team will continue to look after them and make them as comfortable as possible at the end of their life.

Family members sometimes disagree with doctors about treatment choices. They might have hope that the person will recover if given time, or they might believe that the person would not wish to continue living in those circumstances.

Whatever your views and those of your family, it's important to have a discussion with the doctors. Their goal will be to do the right thing for the person who has had the stroke. If an agreement can't be reached, the case may need to go to court for a legal ruling. Specialist solicitors can provide legal advice.

The right to decline treatment

If a person has been able to plan ahead, it can be very helpful for their family and the medical team treating them. If they have discussed what they would like to happen if they are very unwell or dying, you can bring this into your discussions with the medical team.

Some people create a written statement about their wish to avoid specific treatments. It can help to give a picture of their views and attitudes about their end of life care. There are also ways you can appoint someone to make decisions on your behalf.

Power of attorney for health and welfare (England, Scotland and Wales)

This is a legal document that allows you to choose someone to make decisions for you, when you're no longer able to make them yourself. You must have the mental capacity (ability) to set one up.

There are different types of power of attorney, so it's important to get advice before making one. Your local Citizens Advice or a solicitor can advise.

Advance decision to refuse treatment

An advance decision, sometimes known as a living will, is a written instruction about refusing specific types of life-sustaining treatment. It's known as an advance directive in Scotland.

An advance decision is a way for someone to make choices in advance, in case they become unable to make a decision in the future. This can include things like being on a ventilator, having CPR (chest compression to restart your heart), or antibiotics.

An advance decision is legally binding in England and Wales, provided it meets legal standards and the person has the mental capacity (ability) to make the decision.

In Scotland and Northern Ireland, they are not legally binding in the same way but are likely to be treated as if they are by doctors, when making decisions.

It is a good idea to get specialist advice about making an advance decision.

Advance statement

You can also create an advance statement, which sets out your preferences, wishes, beliefs and values about your future care. It's not legally binding, but it provides a guide to those who need to make decisions about your care if you lose the ability to make choices yourself.

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions

Cardiopulmonary resuscitation (CPR) is a treatment that may be given if you stop breathing or your heart stops beating. It can involve chest compressions, stimulating your heart with a machine or using a ventilator. Some people choose in advance to let doctors know they do not want CPR if their heart or breathing stops.

They need to have the capacity (ability) to make this decision. The doctor may complete a 'do not attempt cardiopulmonary resuscitation' form (DNACPR) to add to your medical records. The form is not legally binding. To make a DNACPR decision legally binding, you should make an advance decision to refuse treatment (see the '**Advance decision**' section.)

A doctor can also make a DNACPR decision and should discuss this with the person and their family. Visit [nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/](https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/) for more information.

A DNACPR decision only refers to CPR. The person will continue to have all the other appropriate care and treatment they need.

Where to get help and information

From the Stroke Association

Helpline

Our Helpline offers information and support for anyone affected by stroke, including family, friends and carers.

Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100**
Email helpline@stroke.org.uk

Read our information

Log onto [stroke.org.uk](https://www.stroke.org.uk), where you can find easy-to-understand information, videos and an online community to support you. You can also call the Helpline to ask for printed copies of our guides.

Other sources of help and information

End-of-life care and making decisions on someone's behalf

Citizens Advice

Website: citizensadvice.org.uk

Advice and support for legal questions about making decisions on someone else's behalf, care and funding.

Compassion in Dying

Website: compassionindying.org.uk

Tel: **0800 999 2434**

Information and support about advance decisions and end-of-life care.

Dying Matters

Website: dyingmatters.org

Promotes understanding of end-of-life care and bereavement. Visit the website for information about end-of-life care including hospices and advance decisions.

Marie Curie

Website: mariecurie.org.uk

Helpline: **0800 090 2309**

Information and support on all aspects of life with terminal illness, dying and bereavement.

Emotional support

British Association for Counselling and Psychotherapy (BACP)

Website: bacp.co.uk

Tel: **01455 883 300**

Counselling and Psychotherapy in Scotland (COSCA)

Website: cosca.org.uk

Tel: **01786 475 140**

Cruse Bereavement Care (England, Northern Ireland and Wales)

Website: cruse.org.uk

Helpline: **0808 808 1677**

Cruse Scotland

Website: crusescotland.org.uk

Tel: **0808 802 6161**

Cruse aims to enable bereaved people to understand their grief and to cope with their loss through support groups, one-to-one support, information and training.

Samaritans

Website: samaritans.org

Tel: **116 123**

Email: jo@samaritans.org

Offers free, 24-hour confidential emotional support.

Support and information for carers

Age UK

Website: ageuk.org.uk

Advice line: **0800 678 1602**

Support and advice including information about death and bereavement.

Carers UK

Website: carersuk.org

Advice line: **0808 808 7777**

Email: advice@carersuk.org

Provides information on the practical and emotional aspects of bereavement.

Independent Age

Website: independentage.org

Helpline: **0800 319 6789**

Email: advice@independentage.org

Provides information and advice to older people, including an online grief chat service.

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

This guide contains general information about stroke. But if you have a problem, you should get individual advice from a professional such as a GP or pharmacist. Our Helpline can also help you find support. We work very hard to give you the latest facts, but some things change. We don't control the information provided by other organisations or websites.

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Every five minutes, stroke destroys lives. We need your support to help rebuild them. Donate or find out more at stroke.org.uk

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