

# When someone is seriously ill or dying after a stroke

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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 a stroke. Good treatment and care allow people to make the best recovery possible for them. But even with good care, a severe stroke may cause death, or leave someone with severe disabilities and therefore unable to live independently.

## 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's had a stroke, and hospitals will try and accommodate this.

But it is also important to look after yourself. No matter how unwell the person is, it's important you take time to have a meal and try to 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 higher. If someone already has damage to the brain, a second stroke can make them much more unwell. The medical team will discuss with you medications to reduce the risk of another stroke by treating risk factors like blood clotting, high blood pressure, diabetes and heart problems.

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### Swelling in the brain

A severe stroke may 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 severe disabilities.

Deciding what is best for a person can be complex, and the medical team will support their family and loved ones in making a shared decision about treatment.

A patient decision aid explaining the pros and cons of decompressive hemicraniectomy is available from [nice.org.uk/guidance](https://www.nice.org.uk/guidance)

### Complications after stroke

Sometimes, a stroke can lead to other health complications, which can also cause someone to become very unwell. These can happen soon after a stroke or months or years later. It is important to identify and treat these issues if they happen.

These can include:

- **Swallowing problems:** If someone has difficulty swallowing, food and drink may get into their airway and lungs. This can lead to chest infections or pneumonia. See [stroke.org.uk/swallowing](https://www.stroke.org.uk/swallowing) for more information.
- **Being immobile for long periods:** This increases the risk of a deep vein thrombosis (DVT) forming. A DVT is a blood clot that can form 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 pulmonary embolism.)

- **Heart attacks** are a possibility after stroke. They are linked to many of the same risk factors as for stroke.
- **Seizures after stroke:** These have been linked in some studies with an increased risk of disability, and a greater chance of death if seizures occur soon after stroke. See [stroke.org.uk/seizures](https://www.stroke.org.uk/seizures) for more information on seizures.

## When someone is unconscious or in a coma

A more severe stroke can leave a person unable to respond or in a sleep-like state. This is called a coma and means that important parts of the brain are not working properly. 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 avoid complications developing. They also look after the person's comfort and wellbeing.

They will support family members or carers at this difficult time. They should let you know what is happening and discuss what treatments are important for the person. 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 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 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 could try stimulating their senses with music or a favourite scent.

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 of 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.

Someone might have basic reflexes, like blinking at a loud noise or feeling pain. They may open their eyes and sleep and breathe normally. This is sometimes called a vegetative state.

If someone has more signs of conscious awareness, like being able to respond to a simple command or communicate in some way 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 the person is in, ask a member of the medical team. They monitor the patient closely and can tell you about any changes. They can also explain what treatment and support is being given.

If someone can't do things for themselves, like eating and going to the toilet, they may be given help, such as being fed via a tube and having a catheter to drain their bladder. They will be moved to keep limbs flexible and avoid pressure ulcers. Staff will also carry out basic hygiene like brushing teeth and washing.

### Locked-in syndrome

Locked-in syndrome is a very rare condition where someone is conscious, but unable to move or speak. Some people with locked-in syndrome can communicate with others through blinking or eye movements. Locked-in syndrome is usually due to a stroke in the brain stem, a crucial area of the brain that controls movement and other vital body functions.

Ask the doctor what the person is aware of, to help you understand their condition. You can find more detailed information at [stroke.org.uk](https://www.stroke.org.uk) about locked-in syndrome.

## End of life care

End of life care is support for people who will not recover from an illness. This can last for as long as it's needed, and can be hours, days, weeks or months. This aims to maximise the person's comfort and dignity.

This often includes palliative and supportive care, which is holistic treatment to maintain someone's comfort. 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 hospital team and 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.

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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 vary 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, sleep a lot or lose consciousness. They may stop eating and drinking or find it hard to swallow. 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 or suction treatment, 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 charities Marie Curie and Hospice UK also have information. See **page 7** 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. This is often discussed with the person's next of kin or family member if possible.

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 an 'advance decision' document. 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.

Under current law, doctors are not able to take active steps to end a person's life. But they can recommend stopping 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 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.

### **The right to decline treatment**

If a person has been able to plan ahead, it can be very helpful to 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 provide a picture of their views and attitudes about their care. There are also ways to 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 a person to choose someone to make decisions for them, when they're no longer able to make them themselves. The person 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 compressions to restart your heart) or antibiotics. It's a good idea to get specialist advice about making an advance decision.

An advance decision is legally binding in England, Wales and Northern Ireland, provided it has been signed and witnessed and the person has the mental capacity (ability) to make the decision.

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

### **Advance statement**

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

### **Do not attempt cardiopulmonary resuscitation (DNACPR) decisions**

Cardiopulmonary resuscitation (CPR) is a treatment that may be given if someone stops breathing or their 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.

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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 their medical records. The form is not legally binding. To make a DNACPR decision legally binding, the person 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

#### Stroke Support Helpline

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

Call us on **0303 3033 100**,  
Textphone **18001 0303 3033 100**  
Email [helpline@stroke.org.uk](mailto: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 find a live chat tool to connect you with a grief counsellor.

You can also call the Stroke Support 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](https://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](https://compassionindying.org.uk)

Tel: 0800 999 2434

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

#### Hospice UK

Website: [hospiceuk.org](https://hospiceuk.org)

Promotes understanding of end-of-life care and bereavement. Offers information on end-of-life care, including hospices and advance decisions.

#### Marie Curie

Website: [mariecurie.org.uk](https://mariecurie.org.uk)

Support line: 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](https://bacp.co.uk)

Tel: 01455 883 300

#### Counselling and Psychotherapy in Scotland (COSCA)

Website: [cosca.org.uk](https://cosca.org.uk)

Tel: 01786 475 140

#### Cruse Bereavement Care (England, Northern Ireland and Wales)

Website: [cruse.org.uk](https://cruse.org.uk)

Helpline: 0808 808 1677

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

#### Cruse Bereavement Care (Scotland)

Website: [crusescotland.org.uk](https://crusescotland.org.uk)

Tel: 0808 802 6161

#### Samaritans

Website: [samaritans.org](https://samaritans.org)

Tel: 116 123

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Offers free, 24-hour confidential emotional support.

### Support and information for carers

#### Age UK

Website: [ageuk.org.uk](https://ageuk.org.uk)

Advice line: 0800 678 1602

Support and advice, including information about death and bereavement.

#### Carers UK

Website: [carersuk.org](https://carersuk.org)

Helpline: 0808 808 7777

Email: [advice@carersuk.org](mailto:advice@carersuk.org)

Provides information on the practical and emotional aspects of bereavement.

#### Independent Age

Website: [independentage.org](https://independentage.org)

Helpline: 0800 319 6789

Email: [helpline@independentage.org](mailto:helpline@independentage.org)

Provides information and advice to older people, their relatives and carers.

## 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 Stroke Support 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.

You know more than most just how shocking and confusing having a stroke is. Remember you're not alone. We're here for you for as long as you need us.

Learn more about stroke support: **stroke.org.uk**

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