

## Bereavement and stroke

This guide looks at how bereavement can affect people, and explains some of the reasons why someone may not survive a stroke. It also lists sources of support for families and friends.

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### How bereavement can affect you

For many people, bereavement is one of the hardest things that they will have to go through. A sudden death from stroke may be very difficult to cope with. There might not be time to say goodbye, and no opportunity to resolve any difficult feelings. Or someone may survive a stroke, but die weeks or months later. This can affect family and friends in a different way, and is no less serious for those left behind.

When a loved one dies, the people close to them usually experience intense feelings of sorrow and loss. The mourning process may also involve other feelings such as anger, numbness, depression, guilt or even relief. These feelings may be overwhelming.

Many people experience a sort of numbness after the death of somebody close. It may be that this enables them to carry on with the practical side of their everyday life and to make necessary arrangements such as registering the death and arranging the funeral. If you care for other people there may be many other demands upon you as well, and it is possible that this numbness allows you to continue to fulfil these practical duties.

The bereaved person may also experience physical reactions such as loss of appetite or changes in sleep patterns. Chest tightness, fatigue and having trouble concentrating may also be due to emotional strain. You should visit your GP if you have these symptoms, as they may be signs of a physical illness. See the *Professional help* section later in this guide for more information on where to get help with emotional problems.

### About stroke

A stroke is a brain attack. It happens when the blood supply to part of the brain is cut off, killing brain cells. There are two main types of stroke. The most common type of stroke is due to a blocked blood vessel in the brain. This is called an ischaemic stroke, sometimes referred to as a clot. About 85% of strokes are ischaemic. A stroke due to bleeding in or around the brain is called a haemorrhagic stroke. This is often called a bleed, and is sometimes called a brain haemorrhage. About 15% of strokes are haemorrhagic.

There are more than 100,000 strokes a year in the UK. It is the fourth single leading cause of death in the UK, and around one in eight strokes are fatal within the first 30 days.

### Why stroke can lead to death

When someone does not survive a stroke, it is usually due to severe brain injury affecting those parts of the brain that control breathing and the functioning of major organs such as the heart. If someone remains unconscious or very drowsy for more than a few days, their chances of pulling through are lower, especially if they have had a serious stroke. If someone is incontinent it can mean that a large area of the brain has been damaged, and this can mean a lower chance of survival. However, incontinence can have different causes, and you can discuss this with the doctor.

A stroke may cause swelling in the brain, and this build-up of pressure may be life-threatening if it becomes difficult for the brain to continue functioning.

Following a stroke, someone may also be vulnerable to other health complications that may endanger their life. For example, difficulty with swallowing means that food or drink can enter the lungs. This can lead to chest infections such as pneumonia.

If a person is unable to move for a long time after a stroke, this can increase the risk of a deep vein thrombosis (DVT) forming. This is when a blood clot forms in a vein, often in the lower leg. If a part of the clot breaks off and moves around to the lungs, it can cause a blockage to the flow of blood to the lungs, also called a pulmonary embolism. If it's not treated straight away, pulmonary embolism is a potentially fatal condition.

A heart attack can sometimes happen after a stroke. Stroke and heart attack are linked to some of the same risk factors and health problems, so some people may experience both a stroke and a heart attack.

### Consenting to treatment after a stroke

Normally patients have to give consent to any treatment, but if someone is unable to respond while they are having a stroke, doctors will give emergency treatment required. Once the person has recovered and is able to understand the situation, they may be able to agree to or refuse treatment.

But if someone is unable to understand their own condition after a stroke, doctors have to try to speak to the person's relatives or friends before making a decision about the person's care. Doctors will give treatment if they believe it's in the person's best interests.

### Decision to withdraw treatment

If someone can't make decisions themselves and they are being kept alive with life-support treatments, such as being on a lung ventilator, the choice to continue treatment needs to be based on what the person's best interests are believed to be. Healthcare professionals should discuss the options with relatives and friends. If an agreement can't be reached, the case may need to go to court for a legal ruling.

In some cases, doctors may suggest withdrawing treatment, such as if someone has been in a state of impaired consciousness for at least 12 months. Legally, doctors are not able to take active steps to end a person's life. But sometimes medical professionals will recommend that the best thing to do is to stop active treatments such as antibiotics to treat pneumonia, make the person as comfortable as possible and let nature take its course.

## Bereavement and stroke

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To a family member or friend, this may seem as if a person they care about has been 'written off'. Conversely, it can also happen that doctors may want to continue treatment but the family may feel that this would only prolong their loved one's suffering. 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.

### The right to refuse treatment

#### Advance decision (England and Wales)

It is possible for someone to make choices in advance about refusing treatment, in case they become unable to make a decision in the future. An advance decision, sometimes known as a living will, is a written instruction about refusing specific types of life-sustaining treatment. 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 provided you have the mental capacity to make the decision, and has been signed and witnessed.

#### Advance statement (England and Wales)

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.

#### Advance decision (Scotland and Northern Ireland)

In Scotland, this advance decision is known as an advance directive. It is not legally binding, but it is very likely to be respected by medical staff and relatives. Scottish

courts would be likely to respect the views in an advance directive provided the person had the ability to make their decisions when the directive was written.

In Northern Ireland, like in Scotland, if you set out what you want to happen in an advance decision document that is signed and witnessed, it will make it much more likely that your wishes will be respected by family members and medical and legal professionals if you do become unable to make decisions about your own treatment.

### The grieving process

After someone you know dies, your experience of grief will be unique to you. Our rituals around grief differ between communities and cultures. However there are some thoughts and feelings that have been identified as common in any experience of grief – not just after a death. These do not necessarily occur in a particular order. They may overlap and you may not experience any or all of them.

The feelings you have while grieving may include:

- denial
- anger
- bargaining
- depression
- acceptance.

## Denial

You may feel unable to accept that a death (or impending death) has occurred (or will occur). This denial may be subconscious or it may be a conscious choice. It may last for a very short time – a few minutes or hours – or it may persist for much longer.

## Anger

Feelings of anger and bitterness are common. Anger can be felt towards any number of people or circumstances. For example, you may feel angry with the deceased person who you feel has left you. This can lead to feelings of guilt. You may also feel angry with doctors or other medical staff for not doing enough, or relatives and friends who remain distant.

## Bargaining

This may occur when a person or somebody close to them has a life threatening illness, or after a loved one has died. If the person has religious or spiritual faith, they may attempt to make a deal with their god or higher power, in order to preserve themselves or their loved one from death.

## Depression

This is common and may involve many different symptoms including prolonged feelings of anxiety, tearfulness, hopelessness, lack of sleep or disturbed sleep, loss of appetite, loss of interest in everyday activities or difficulty concentrating or making decisions.

## Acceptance

You may experience difficult emotions involving sorrow, anxiety, fear, regret or guilt. You may begin to move towards recognising that life will never be as it was, and that you have to go on without the presence of your loved one. Acceptance begins when the bereaved person is able to accept that the deceased person is not coming back.

It is normal to experience a continuing connection with the person who has died and for this to change over time. You may feel that your connection to your loved one is diminished, but will never go entirely. For some people this period may coincide with a re-evaluation of their own identity or situation, and sometimes results in people making changes in their own life.

There is no set period of time for grieving. Some people may feel they have become 'stuck' on a particular stage of grief. For instance, you may feel that you are not able to connect with feelings and a sense of numbness and disbelief just goes on and on. This may be normal for you and is probably not harmful. However some people, who have not had an opportunity to grieve, may find that they experience physical symptoms or periods of depression in the years following a loss. It may help to seek professional support if you are affected in this way (see *Professional help* later in this guide).

## Carers and bereavement

Many carers find that their caring role is the focus of their daily life. If a carer has devoted their energies to a loved one over many years, they may also have become increasingly isolated, losing touch with their own friends or interests.

The loss for carers may lead to very mixed and conflicting emotions. Feelings of grief and sadness may be combined with guilt or relief. As well as trying to cope with the loss of their loved one, carers also face life without their role as a carer, with contacts or networks built up as part of their caring role also coming to an end.

A carer's bereavement may not only have a huge emotional impact, but may also result in significant practical and financial changes too. Carer support organisations can provide advice and support on the emotional and practical aspects of loss (see *Where to get help and information* later in this guide).

## Children and young people

Children experience the pain of grief like adults, but they may have difficulty understanding or expressing their feelings. Their distress can come out in different ways such as troubled sleep, problems at school or anger and acting-out behaviour. Children often move quite quickly between extremes of emotion, one moment being very upset, the next playing. It is common for younger children to think that a death was their fault in some way, and they may need reassurance.

The best way to understand what children are thinking and feeling is to listen to them carefully. Try to include them in discussions about the person who has died. For example,

talk to them about funeral preparations. Trust your instincts as a parent. Remember, it's OK for you and your children to feel sad, angry and confused, as well as all the other emotions that you experience.

## Supporting family and friends

Bereavement can be very isolating because other people, even those close to the bereaved person, may feel awkward or afraid of saying the 'wrong' thing. A person will almost certainly appreciate it if you acknowledge their loss, even if you don't know what to say. Some people want company. They may want to talk about how they feel and about the deceased person. Others may prefer some time alone, while knowing that people are there for them. People have different needs, and it is important to let them decide what support they want. Practical help like shopping, cooking, and childcare may be greatly appreciated.

## Professional help

You may welcome professional support in coping with grief, either emotionally or with the physical effects, such as lack of sleep. It may help to talk to your doctor. They can give you a general health check-up, prescribe medication, such as anti-depressants or sleeping tablets, and refer you for counselling. Counselling may also be available through your place of work, university, college or school, some charities and privately. A counsellor can offer you a safe and confidential space to talk through what you are experiencing, without worrying that you are burdening or upsetting people. Counselling is available in one-to-one or in groups for children and families too. See the *Emotional support and counselling* resources later in this guide.

### 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

#### What to do when someone dies

##### Age UK

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

**Advice line:** 0800 678 1174

Provides many useful leaflets including *What to do when someone dies* and *Bereavement: Support after a death*.

##### Citizen's Advice

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

Offers advice on what to do after a death, including help with financial matters and arranging funeral services.

##### GOV.UK

**Website:** [www.gov.uk/after-a-death](http://www.gov.uk/after-a-death)

Has information about what to do after someone dies, including details of how to register a death, understanding wills and probate, and claiming Bereavement Support Payments.

##### NI Direct (Northern Ireland)

**Website:** [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

The official government website for Northern Ireland citizens. Has a checklist of things to do when someone dies and information on registering a death in Northern Ireland.

##### Scottish Government

**Website:** [www.gov.scot](http://www.gov.scot)

Publishes a booklet called *What to do after a death in Scotland... practical advice for times of bereavement*.

#### Emotional support and counselling

##### British Association for Counselling and Psychotherapy (BACP)

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

**Tel:** 01455 883 300

**Email:** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

Sets standards for people working in counselling. You can use their website to search for a counsellor or therapist in your area and get more information about counselling and therapy.

##### British Psychological Society (BPS)

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

**Tel:** 0116 254 9568

**Email:** [enquiries@bps.org.uk](mailto:enquiries@bps.org.uk)

Sets standards and provides information to the public about psychology. You can search on their website for a psychologist.

## Bereavement and stroke

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

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

**Tel:** 01786 475 140

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

Provides information about finding a counsellor in Scotland.

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

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

**Helpline:** 0808 808 1677

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

### **Cruse Bereavement Care (Scotland)**

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

**Tel:** 0845 600 2227

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

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.

### **Hope Again**

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

A website designed by young people for young people and run by Cruse Bereavement Care. It features personal stories and creative work.

### **Samaritans**

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

**Tel:** 116 123

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

Offers 24-hour confidential emotional support.

### **Carer support organisations**

#### **Carers UK**

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

**Advice line:** 0808 808 7777

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

Provides information on the practical and emotional aspects of bereavement.

#### **Independent Age**

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

**Helpline:** 0800 319 6789

**Email:** [advice@independentage.org](mailto:advice@independentage.org)

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

### **For bereaved children**

#### **Child Bereavement Charity**

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

**Helpline:** 0800 028 8840

**Email:** [support@childbereavementuk.org](mailto:support@childbereavementuk.org)

Confidential support and information for anyone affected by the death of a child or who is caring for a bereaved child.

#### **Winston's Wish**

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

**Helpline:** 08088 020 021

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

Provides bereavement support, information, advice and guidance for children and young people, and advice to parents, carers and teachers on supporting bereaved children.

## 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](mailto:feedback@stroke.org.uk).

### Accessible formats

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

### Always get individual advice

Please be aware that this information is not intended as a substitute for specialist professional advice tailored to your situation. We strive to ensure that the content we provide is accurate and up-to-date, but information can change over time. So far as is permitted by law, the Stroke Association does not accept any liability in relation to the use of the information in this publication, or any third-party information or websites included or referred to.

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We rely on your support to fund life-saving research and vital services for people affected by stroke. Join the fight against stroke now at [stroke.org.uk/fundraising](http://stroke.org.uk/fundraising)  
**Together we can conquer stroke.**

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