Bereavement and stroke

Losing a loved one is one of the hardest things to come to terms with. This factsheet explains some of the reasons why someone may not survive a stroke and how to support somebody who is bereaved. It also provides further sources of support for families and friends.

A stroke can happen suddenly and for many people it is life-changing. A stroke happens when the blood supply to part of the brain is interrupted. The most common type of stroke happens when there is a blockage in an artery that carries blood (taking oxygen) to the brain (called an ischaemic stroke).

Strokes that happen when a blood vessel bursts, causing bleeding within the brain or on the surface of the brain (called a haemorrhagic stroke), are less common.

Stroke occurs approximately 152,000 times a year in the UK. It is the fourth single largest cause of death in the UK and around one in eight strokes are fatal within the first month.

**Why do some people not survive a stroke?**

When someone does not survive a stroke, it is usually due to severe brain injury damaging 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.

Their chances of survival are also lower if they are still incontinent after a week.

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 windpipe and then the lungs. This can lead to chest infections such as pneumonia.

If a person is unable to move for a long time, this can increase the risk of pulmonary embolism. This is when a blood clot forms in a vein (often in the lower leg) and the clot moves around the body to the lungs, blocking the flow of blood. Pulmonary embolism is a potentially fatal condition.

A common cause of death in the weeks after a stroke is a heart attack. Although treatments to reduce the risk of stroke should also reduce the risk of heart attack, sadly sometimes it cannot be prevented.
Bereavement and stroke

Making difficult decisions

If someone is unconscious after a stroke, or their stroke has affected their communication or thinking, they may not be able to make decisions about their treatment.

Often a stroke is sudden and unexpected and the person will not have expressed what they want to happen in this situation. In this case, the doctor in charge of the person’s care has overall responsibility for decisions about their treatment. They must consult with those closest to the person and the rest of the healthcare team. When making decisions about treatment, doctors will begin by assuming that all reasonable steps should be taken to prolong a person’s life.

It is possible for someone to make decisions about their treatment in advance, in case something happens in the future. An advance decision is a written instruction concerned with the refusal of life-saving treatment. In England or Wales an advance decision is legally-binding provided certain conditions are met. In Scotland and Northern Ireland, an advance decision isn’t legally binding. However, doctors must take it into account when making decisions on someone’s behalf. An advance decision is known as an advance directive in Scotland.

Legally, doctors are not able to take active steps to end a person’s life. However, sometimes 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. This is sometimes called ‘withdrawal of treatment’.

If doctors feel that it would be best to withdraw treatment, you may feel that a person you care about has been ‘written off’. On the other hand, the doctor may want to continue treatment but you may feel that this would only prolong your loved one’s suffering. Whatever your views and those of your family, discuss them with the doctor. Their goal will be to do the right thing for the person who has had the stroke.

Coping with bereavement

Sadly, despite treatment, many people will not survive a stroke, leaving their carers, families and loved ones bereaved. For many people, bereavement is one of the hardest things that they will have to go through. A sudden or unexpected death may be particularly difficult to cope with. There is no time to say goodbye, or opportunity to resolve any difficult feelings.

When a loved one dies, the people close to them usually experience intense feelings of sorrow and loss. For many people, the mourning process may also involve many other feelings such as anger, numbness, depression, guilt or relief. These feelings may be almost overwhelming. The bereaved person may also experience physical reactions such as loss of appetite or changes in sleep patterns. Chest tightness, muscle weakness and lack of energy are normal but can be worrying. Talk to your GP if you have any concerns.

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. (See Useful resources for advice)
Bereavement and stroke

on these procedures. 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.

Everyone’s experience of grief is different and is personal to them. Our rituals around grief also 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.

They are explained in more detail below:
• 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.
Bereavement and stroke

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 page 5).

**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 Other useful contacts).

**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.

Unlike adults, 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 and don’t be afraid to ask for help if you need it. Remember it’s OK for you and your children to feel sad, angry and confused – and it’s OK if you don’t.

**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, whilst 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 with chores such as shopping, cooking, and child-minding may be greatly appreciated.
Bereavement and stroke

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 make referrals to an NHS counsellor.

Counselling may also be available through your place of work, university, college or school, some charities and privately (see Other useful contacts). 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 one-to-one or in groups for children and families too.

How can I find out more?

Talk to us
At the Stroke Association, our Stroke Helpline can give you information about stroke and tell you about services and support available in your local area.

Call us on 0303 3033 100 (Monday to Friday, 9am–5pm) or email info@stroke.org.uk

Get online
We have lots of information about stroke on our website. Go to stroke.org.uk

Read our publications
We also produce a range of other leaflets and factsheets about stroke and related issues. You can download these for free or order a printed copy to be posted to you via our website stroke.org.uk or by calling the helpline on 0303 3033 100.

Useful resources

The Citizen’s Advice Bureau (CAB) website www.adviceguide.org.uk includes information about what to do after a death which applies to England, Wales and Northern Ireland.

The UK Government has information about what to do after someone dies. Visit www.gov.uk/after-a-death

There’s also information about registering a death in Northern Ireland on the NI Direct website. Visit www.nidirect.gov.uk

The Scottish Government publishes a booklet called What to do after a death in Scotland... practical advice for times of bereavement. Visit www.gov.scot to find it or call 0131 244 3581 to order a print copy.

Age UK provides many useful leaflets including What to do when someone dies and Bereavement: Support after a death. Visit www.ageuk.org.uk to find them or call their advice line on 0800 169 6565.

Hope Again is a website designed by young people for young people and is run by Cruse Bereavement Care. It features personal stories and creative work. Visit www.hopeagain.org.uk

The book Death and how to survive it: A unique, practical and uplifting guide to coming to terms with the loss of your partner by Kate Boydell is published by Vermilion. The author’s husband died of complications following heart surgery, leaving her a widow with two children. There’s also information on the author’s website. Visit www.merrywidow.me.uk
Bereavement and stroke

The book *At a stroke: The rollercoaster of living with someone who has had a stroke* by Huw Watkins is published by White Ladder Press. The author’s wife died six months after having a brainstem stroke. He describes the ‘emotional rollercoaster’ of their journey including advice for those who are bereaved.

Other useful contacts

If you’re looking for more information the following organisations may also be able to help. All are UK wide unless otherwise stated.

Please note that details of these organisations are for information only. We are not recommending or endorsing anyone by including them in this factsheet.

**Cruse Bereavement Care**
(England, Northern Ireland and Wales)
**Website:** www.cruse.org.uk
**Helpline:** 0844 477 9400
**Email:** helpline@cruse.org.uk

**Cruse Bereavement Care**
(Scotland)
**Website:** www.crusescotland.org.uk
**Tel:** 0845 600 2227
**Email:** 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.

**Samaritans**
**Website:** www.samaritans.org
**Tel:** 08457 90 90 90
**Email:** jo@samaritans.org
Offer 24-hour confidential emotional support.

**British Association for Counselling and Psychotherapy (BACP)**
**Website:** www.itsgoodtotalk.org.uk
**Tel:** 01455 88 33 00
**Email:** 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
**Tel:** 0116 254 9568
**Email:** enquiries@bps.org.uk
Sets standards and provides information to the public about psychology. You can search on their website for a psychologist.

**Counselling and Psychotherapy in Scotland (COSCA)**
**Website:** www.cosca.org.uk
**Tel:** 01786 475 140
**Email:** info@cosca.org.uk
Provides information about finding a counsellor in Scotland.

**Carer support organisations**

**Carers UK**
**Website:** www.carersuk.org
**CarersLine:** 0808 808 7777
**Email:** advice@carersuk.org
Provides information on the practical and emotional aspects of bereavement.

**Independent Age**
**Website:** www.independentage.org
**Advice line:** 0800 319 6789
**Email:** advice@independentage.org
Provides information and advice to older people, their relatives and carers.
Bereavement and stroke

For bereaved children

Child Bereavement Charity
Website: www.childbereavementuk.org
Tel: 0800 02 888 40
Email: 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
Helpline: 08452 03 04 05
Email: 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.

How did we do?
Your feedback will help us to improve our publications, making sure that they answer your questions and are easy to understand.

To let us know what you think of this factsheet email us at feedback@stroke.org.uk
Bereavement and stroke

About our information
We are committed to producing clear, accurate and unbiased information for stroke survivors, their families and friends. To produce our publications we use information from professional bodies and other reliable sources including NICE, SIGN, Royal College of Physicians, medical journals and textbooks. To request a list of sources email feedback@stroke.org.uk

© Stroke Association
Factsheet 23, version 1.1
Published March 2015.
Next review March 2016.
Item code: A01F23

The Stroke Association is a charity. We rely on your support.
Text STROKE 5 to 70300 to donate £5. 100% of your donation goes to the Stroke Association. Find out how your support helps at stroke.org.uk/savelives

Stroke Association is a Company Limited by Guarantee, registered in England and Wales (No 61274). Registered office: Stroke Association House, 240 City Road, London EC1V 2PR. Registered as a Charity in England and Wales (No 211015) and in Scotland (SC037789). Also registered in Northern Ireland (XT33805) Isle of Man (No 945) and Jersey (NPO 369).