

# Bereavement and grief after stroke

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

# This guide looks at the emotional impact of bereavement when someone you know dies from a stroke.

When you lose someone to stroke, it can be a very emotional time, as well as a time of great change. It can be very difficult for family members and friends to cope with.

Sometimes a death from stroke is very sudden, but even for those who know their loved one is dying, it can come as a great shock when the end comes. There might not be time to say goodbye, and you might not get the chance to say the things you wanted to say.

When someone has a stroke, the medical teams work hard to help them recover, but it's not always possible to prevent another stroke or serious illness affecting them. Stroke and other illnesses like infections can be very sudden and have a serious impact. So you might not get much warning before someone becomes very unwell or dies.

Some people experience feelings of grief before someone who is very ill dies. This is sometimes called 'anticipatory grief'. You may feel sad, worried or angry. It may help to talk through your feelings with family or friends. You can also contact our Stroke Support Helpline.

If you would like to find out more about treatments and care after a severe stroke, visit **stroke.org.uk** to read our guide 'When someone is seriously ill or dying after a stroke' or call our Stroke Support Helpline for a print copy.

### The grieving process

When a bereavement happens, everyone experiences the loss and grief in their own way and in their own time. Even if you had a difficult relationship with the person, you might still have a strong reaction to their death and go through a grieving process.

After someone dies, your experience of grief will be unique to you. Our rituals for grief and mourning differ between communities and cultures. But there are some thoughts and feelings that have been identified as common in any experience of grief. These don't necessarily happen in a particular order. They may overlap and you may not experience any or all of them.

### Bereavement and grief after stroke

The feelings you may have while grieving include:

### **Shock and pain**

The pain of a bereavement can be very powerful or overwhelming. It can take some time to acknowledge what has happened. You might carry on as if nothing has happened, or avoid doing things that refer to your loss. You might feel disorientated, or as if you've lost your sense of purpose. This can last a short time, or carry on for a longer period.

### **Anger**

Feeling angry is natural, whether it's anger at the unfairness of death or feeling angry with the person who has died for leaving you, or with people you might blame for their death. You may also feel angry with relatives and friends for not doing enough.

### Longing

You might think about the person who has died, imagine you see them or have dreams about them. You could think about things that have happened in the past and what you should have said and done.

### Guilt

It's common to have feelings of guilt, and some people worry that they should have done more to help or feel bad about something that happened in the past. Try to be kind to yourself and give yourself time.

### Sadness and low mood

Sadness is a natural response when someone dies, but it might not happen right away. For some people, feeling sad might come some time after the initial shock.

If feelings of sadness are affecting your mood and your ability to enjoy life, it could be a sign of low mood or depression. Things to look out for include sleep problems, tearfulness, loss of appetite, losing interest in things you enjoy, or trouble with concentration. If you feel that low mood or depression are affecting you, contact your GP for help and treatment.

### **Physical symptoms**

These may include problems with sleeping and eating, chest tightness, fatigue and trouble with concentration. If this happens, it's a good idea to contact your GP who can check you for any physical illness and give you ideas for finding emotional support.

### Coping with grief

Everyone grieves in their own way. You might experience emotions like sadness, sorrow, anxiety, fear, regret or guilt. You might cry all the time or not be able to cry. You might feel lonely or isolated.

If you had a difficult relationship with the person who died, or were estranged, your reaction could be complex. For example, you might not miss someone you haven't seen for years, but still have a strong reaction to their death. It could bring up regrets and longings, anger or even relief.

The pain of loss should lessen over time, but it can be a very gradual process. Eventually you may begin to move towards recognising that life won't be the same without them there. But there will be new ways of living life.

Nobody can tell you what to feel. But there are some practical things you can try.

- Talk to other people. Be open about your feelings and share memories with family and friends.
- Try to take extra care of yourself by eating well, getting some sleep and staying active.
- Be kind to yourself. Give yourself time to grieve and seek help with things like housework and childcare if you need a break.
- Keep the person's memory alive by writing down stories or making an album of photographs. Visit somewhere meaningful to them or hold a celebration of their life.
- Commemorate the person by dedicating a park bench, naming a new rose, or making a memory quilt using fabric or photographs. Some people decide to raise funds for a cause or donate to charity in the person's name.

## Bereavement support and grief counselling

Painful feelings can sometimes come back, even after you have come to accept your loss. There is no right or wrong way to grieve and no set timetable. But some people can feel like they have become stuck in certain feelings over a long period and it's affecting their daily lives. Or grief can be buried or delayed and emerge as low moods or depression months or years later.

It can be helpful to get professional support such as talking therapy.

In England, you can refer yourself for an NHS talking therapy. Visit nhs.uk/nhs-services/mental-health-services to find a service near you. You can still ask your GP for a referral if you prefer. In Scotland, Wales and Northern Ireland, you can ask your GP to refer you for help.

Some people choose to pay privately for therapy or counselling. You can look for accredited professionals via several websites listed in the 'Where to get help and information' section.

For more ideas on how to get help, call our Stroke Support Helpline, or contact an organisation dedicated to supporting people after bereavement, such as Cruse.

The Samaritans have a 24-hour helpline to support people who are finding it hard to cope with difficulties including bereavement. You can call them free on 116 123.

The NHS 111 helpline can help you find urgent help with mental health at any time. Call 111 (or 18001 111 from a textphone).

### Carers and bereavement

Many carers who have supported someone 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. Contacts or networks built up as part of their caring role may also come 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. We have information on financial help which may be available after a bereavement at stroke.org.uk/financial-support

Carer support organisations can also provide advice and support on emotional and practical matters following a loss. See 'Where to get help and information' later in this guide.

### Children and young people

Children don't always show their emotions in the same way as adults. A sad child could show their feelings through angry outbursts, sleep problems or appearing withdrawn or anxious, for example. They can move quite quickly between extremes of emotion. A child can be very upset one moment, and seem completely fine the next. But like adults, they need time to go through the grieving process.

Younger children might believe that a death was their fault or that they can bring the person back. They might not say this out loud, but you can encourage them to talk about their feelings. Reassure them and answer any questions they may have. Let them know that it's okay to enjoy their usual activities and have fun with friends if they want to.

How you explain things and answer questions will depend on the child. You know your child best, so you'll know whether you can get them involved in discussions about a funeral or ways to celebrate the person's life. Let them express their feelings and talk about the person if they want to. It's a good idea to be direct rather than using euphemisms like 'gone away' or 'gone to sleep', as this can be confusing.

If you want more advice, you can call Child Bereavement UK's confidential helpline on **0800 02 888 40**.

### Supporting a bereaved person

If you're supporting someone who has been bereaved, it's normal to worry or feel awkward about saying the 'wrong' thing. But someone who's been bereaved will almost certainly appreciate it if you acknowledge their loss, and won't mind too much how you say it.

They may want to talk about how they feel and about the deceased person. They may appreciate having someone to listen. Some people want company, while others may prefer some time alone. You could let them know you are there for them if they need you.

People have different needs and it is important to ask them what support they want. Practical help like shopping, cooking or childcare may be greatly appreciated.

# 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** 

### Read our information

Log onto **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 call the Stroke Support Helpline to ask for printed copies of our guides.

### Supporting in a loved one's memory

More information about supporting the Stroke Association in your loved one's memory can be found at stroke.org.uk/in-memory-giving

# Other sources of help and information

### What to do when someone dies Citizens Advice

Website: citizensadvice.org.uk

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

### GOV.UK (England and Wales)

Website: 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: nidirect.gov.uk/articles/documents-and-information-needed-when-someone-dies

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

### **Scottish Government**

Website: mygov.scot/when-someone-dies Provides advice on what to do after someone dies and information on financial help and support organisations in Scotland.

### **Emotional support and counselling**

# British Association for Counselling and Psychotherapy (BACP)

Website: bacp.co.uk
Tel: 01455 883 300
Email: bacp@bacp.co.uk

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

# Counselling and Psychotherapy in Scotland (COSCA)

Website: **cosca.org.uk** Tel: **01786 475 140** 

Email: info@cosca.org.uk

Provides information about finding a counsellor in Scotland.

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

Website: cruse.org.uk Helpline: 0808 808 1677

Cruse 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 Scotland Bereavement Support**

Website: crusescotland.org.uk

Tel: **0808 802 6161** 

Email: info@crusescotland.org.uk

### Good Life, Good Death, Good Grief (Scotland)

Website: **goodlifedeathgrief.org.uk**Promotes understanding of end-of-life care and bereavement. Visit the website for information about end-of-life care, including hospices and advance directives.

### **Hospice UK**

Website: hospiceuk.org

Visit the website for information about endof-life care, including hospices, advance decisions and support for carers.

### **Samaritans**

Website: samaritans.org

Tel: **116 123** 

Email: jo@samaritans.org

Offers 24-hour confidential emotional

support via their helpline.

### **Young Minds**

Website: youngminds.org.uk

Information and advice about children and young people's mental health, including a parents' guide to supporting children after a bereavement.

Carer support organisations	Your notes
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: helpline@independentage.org Provides information and advice to older people, their relatives and carers.	
For bereaved children	
Child Bereavement Charity Website: childbereavementuk.org Helpline: 0800 028 8840 Email: helpline@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: winstonswish.org Helpline: 08088 020 021 Email: ask@winstonswish.org 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

### **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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