



After someone has died

*A guide for relatives
and carers*

Because every day matters

www.hospiscare.co.uk

Registered charity no. 297798



Hospiscare

Caring in the heart of Devon

If you have picked up this leaflet, the chances are that someone you love has just died or maybe you know they are about to. We recognise that every death is tragic and also that no two people are alike in how they will experience grief. Each person will find the support they need in different ways.

Death is part of life's cycle and all of us will experience loss in our lives but whether it was expected or not, death can still come as a huge shock. Culturally, we often shy away from conversations about death and dying and people from different cultural backgrounds will have different ways of mourning and supporting each other.

This booklet is designed to help you understand a little bit more about grief and bereavement and outline the support available from Hospiscare now and in the future. The information is also available on our website. If you would like additional copies, please contact the Supportive Care Team.

Contact us

If you would like to speak to the supportive care team, you can contact us on 01392 688008 or email supportivecare@hospiscare.co.uk . For more information, visit www.hospiscare.co.uk

If you need urgent help, please contact your GP or call NHS direct on 111

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What is grief?

The death of someone close to you can be an emotionally traumatic experience. Grief is not an illness. It is not a weakness. It is a healthy and necessary response and experience.

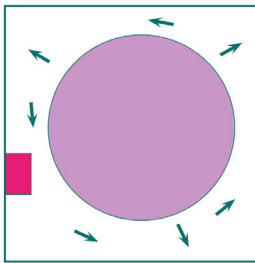
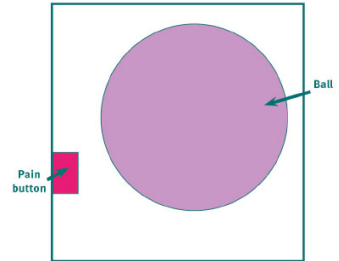
Grieving is a highly individual experience; there's no right or wrong way to grieve. Even if you knew your loved one was dying, there is still a sense of shock when the death occurs. Most bereaved people come through grief with the help of family and friends.

Inevitably, the grieving process takes time. Healing happens gradually; it can't be forced or hurried—and there is no 'normal' timetable for grieving. Some people start to feel better in weeks or months. For others, the grieving process is measured in years. Whatever your grief experience, it's important to be patient with yourself and allow the process to naturally unfold.

Grief can make you feel like you are on an emotional roller coaster where one minute you feel able to cope and the next overwhelmed. As time passes, the balance between the good and bad days will start to shift and you will start to have more good days and fewer bad. The changes are gradual and the balance will be different to others after the same length of time.

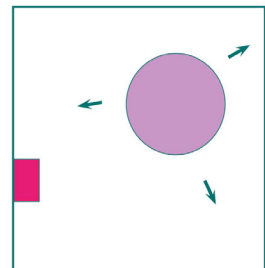
The ball and the box

Some people find it helpful to think of grief as being like a box with a ball in it. This helps us understand how feelings can change over time but also continue to be triggered at random moments.



In the early stages, the ball is very big and frequently hits the pain button. It rattles around on its own and hits the button over and over again, sometimes so much that it feels like you can't stop it - you can't control it – it just keeps hurting.

As time goes on, the ball gets smaller. It doesn't disappear completely and when it hits the pain button, it's just as intense, but generally, it is easier to get through each day.



This analogy can help to talk about how you're feeling each day. You may say that some days the ball is really big, endlessly hitting the button, and you just have to wait until it gets smaller again.

Emotional aspects of grief

Shock and disbelief: Immediately after a loss, it can be hard to accept what has happened. You may feel numb or have trouble believing that the loss is real.

Sadness: Profound sadness is one of the most universally experienced symptoms of grief. You may have feelings of emptiness, despair, yearning, or deep loneliness. You may also cry a lot or not at all.

Guilt: Guilt is a common reaction and can take different forms. You may feel guilty about things you said or didn't get a chance to say. You may feel guilty that you couldn't protect your loved one or be with them when they died, even if there was no possible way for you to have been there.

Anger: You may feel angry and resentful and this is an understandable response to the loss. Death can seem cruel and unfair and you may feel the need to blame someone for the injustice of your loss.

Fear: You may feel anxious, helpless, or insecure and even have panic attacks. The death of a loved one can trigger fears about your own mortality as well as fear of facing life without that person.

Physical aspects of grief

We often think of grief as a strictly emotional process, but grief often involves physical symptoms such as:

- Feeling tired with no energy to perform simple tasks
- Feeling unable to sleep properly
- Nausea, or an unsettled stomach
- Lowered immunity; you may pick up bugs like colds more easily
- Aches and pains such as headaches, back pain and muscular aches
- Changes to your appetite such as loss of interest in food or eating for comfort

Since the COVID-19 pandemic, most people are even more aware of little changes to their health in case they are infected with the virus. Some of the symptoms above are “normal” symptoms of grief but they could also be symptoms of the virus and you should follow the latest government advice if you suspect you have coronavirus symptoms.

How might grief affect my behaviour?

You might be:

- Irritable, angry
- Restless and unable to settle and relax
- Wanting to keep busy
- Tearful or unable to cry
- Preferring your own company and rejecting others
- Finding it difficult to stay in or difficult to go out

Understanding that these feelings, thoughts and behaviours can be ‘normal’ grief reactions may reassure you at this time. No one can know how long you will feel this way. Your grief will change and evolve as, in time, you adjust to living your life whilst maintaining the sense of the bond with the person who died.

As this is a highly emotional time, it is advisable not to make any major decisions unless you have to. Most decisions about the future, for example what to do with your loved one’s possessions, will wait until you are better able to think things through. If you cannot avoid having to make important decisions, try to talk them over with someone you can trust who can help you to consider your options.

Grief when you don't get to say goodbye

When you experience the death of a loved one, even if it is expected, it can leave you feeling stunned. When that death is unexpected, you also have to deal with the shock of the sudden loss. You can feel a loss of security and confidence in the world because you have had someone snatched away from you without warning.

Not having a chance to prepare and say goodbye are really difficult to come to terms with. There was no gradual transition, no time to make changes in yourself or your expectations about your life. It might feel like time stopped and there is a strong sense for before and after; how your world 'should' be and how it is now. The death may continue to feel inexplicable for a long period of time.

You may find yourself looking back at the time leading up to the death and searching for clues that you might have missed. This tendency to reconstruct events in your mind is quite common. This retrospective construction of events can become more troublesome if you start to perceive that you might have been responsible for 'missing something'.

The impact of any loss can last a lifetime and can change how we think about the world. It can prompt you to make more time for those that are still here. You know that tomorrow is not a guarantee for anyone, especially when you have experienced a sudden death. This can help you keep what is most important to you in mind.

Grieving in uncertain times

The whole world changed in the early part of 2020 and it is likely that the COVID-19 pandemic will have played some role in your recent loss. It may or may not have been the cause, but it is likely to have impacted on your loss and you may have many “what if” questions. You may question the treatment your loved one was able to have and whether it was because of the changes brought about by COVID-19 that your loved one died.

Grief is described as being a lonely experience anyway and you may feel more isolated and cut off from those that you would normally turn to for support.

Your loved one may have been taken into hospital and you couldn't go with them or you may have been unable to visit your loved one at home. These circumstances can make feelings of loneliness more intense.

Government restrictions may be limiting the type of funeral service you are able to have. Many people have found it really difficult not being able to mourn in ways that are in keeping with traditions and cultural heritage.

Please call the team on 01392 688008 if you would like to find out more about the additional support we may be able to offer you.

Alternatives when you cannot attend a funeral

When it is not possible to attend a service or funeral, you may feel unsettled, guilty or worried you will not have an opportunity to say goodbye to your loved one. You may feel concerned that you will not be able to experience the ritual, symbolism and collective grieving that occurs at a funeral. Planning the funeral is often what people focus on immediately after a death.

We have put together some ideas that you could consider as an alternative way of memorialising your loved one. You could also seek additional information by phoning your religious or spiritual guide or looking online.

Create a memory area: This could be a collection of photos or objects that reminds you of your loved one. You may want to light some candles or write messages on cards. Set aside a specific time to do this. If you have children, they may want to draw pictures or write a letter to add to the area.

Make a time to have a memorial: You could have a dinner with those in your household or agree a time to call others to virtually join you. You could choose a meal for everyone to cook so that you feel together, even if you can't be physically.

Make a memorial book: You could ask friends and family to send you photos, stories, memories and songs and make them all into a book. Spending time doing this on your own or with others could be a positive way to remember the person you have lost.

How can I help myself?

Prioritising self-care when you are grieving is of great importance.

Ask for help: Recognise when things are getting too much and reach out. Every loss is tragic; talking about how you are feeling with friends and family can be helpful. You can also speak to one of our team; you can find their contact details at the front of this booklet.

Look after your physical health: The mind and body are connected. Try to maintain a routine and take care of yourself by eating well, exercising and getting enough rest. Be cautious of using alcohol or drugs to numb the pain of grief or lift your mood artificially.

Try to maintain your hobbies and interests: You may need to find different ways of doing this from home. There are many online support groups and telephone support services available.

Be kind to yourself: Your grief is your own; no one can tell you when it's time to 'move on'. Let yourself feel without judgment or embarrassment. It's okay to be angry, to cry or not to cry. It's also okay to laugh and to find moments of joy.

Plan ahead for grief 'triggers': The 'firsts' are difficult; the first birthday or anniversary without your loved one may remind you of the moments you would have shared. Prepare yourself for the emotional hit and know that it's completely normal. Get in contact with friends and family and let them know the day is coming.

What can I read or listen to?: There is additional information on our website, including an up-to-date reading list for adults and children. Many of the books are also available

as audiobooks. If you would like a copy of either reading list, please call the team to request one.

There are also podcasts which you might find helpful.

How can I help someone else?

Stay in touch: If you know someone has been bereaved recently, try and stay in touch. If they ask you to attend a virtual remembrance service and you are able to call in, try and do that. Letting others know that you are thinking of them, albeit from a distance, can make all the difference. Just being there to listen can really help.

Find out what local services are available:

Many local support groups have been set up to help. The Supportive Care Team may be able to offer further support or sign post you to another organisation or charity that can. Please call 01392 688008 for further details or have a look at our website: www.hospiscare.co.uk

How can I support my children?

It is natural to want to protect children from things which hurt them, but when someone dies, we cannot hide that fact, or hide the way that we feel.

How children understand death depends on their stage of development and each child is different in their reaction:

- **Under 5 years-old:** children don't understand that death is permanent, or what it entails. It is okay to gently explain that the person who has died can't come back again.
- **Between 6 and 12 years-old:** children know about death but they may not always understand emotions linked to it.
- **By 8 or 9 years-old:** children may start to understand death in the way that adults do, but may still hope that if they are very good, the person who has died will come back.
- **Teenagers:** young people are old enough to understand that death means a major change or loss in their life. They may cope in ways that are difficult for you to deal with. Much like an adult, they need to know that feelings like this are normal. Encourage them to talk to someone they trust, give them space when they need it and keep a close eye on them.

Be honest and open: If you provide a child with simple information, they will come back and ask more questions if they need to. Try to pick a time when you are not feeling too overwhelmed yourself.

Children might ask you questions you do not know the answer to. Say so. Ensure they are able to approach you with their questions. Be mindful about what they are accessing online and how much exposure they have to information.

Be their example: Children often pick up on how the adults around them are feeling, even if you try to act as if everything is normal. It can be helpful to explain to your child how you are feeling and why, as well as modelling coping techniques. Trying to maintain your routine is helpful for children.

Children's adjustment is largely dependent on how their parents/care givers/adults adjust. Let them know that it is ok to worry or be sad and support them through these feelings.

Children might also pick up on things you are worried about, for example financial or job concerns. Try and have these conversations away from children if at all possible.

Start early: Children will have heard about death before and may have experienced the death of a pet. We often underestimate a child's ability to deal with change and shy away from questions about death to protect them. If children feel unable to ask questions, it can make it scarier for them and reinforce the idea that they have to deal with what is happening on their own. Helping children to understand death and to communicate their feelings will help them to cope.

Be clear: Children can sometimes think that they are responsible for bad things happening. Give simple explanations about what has happened and lots of reassurance that nothing they said or did made it happen. Avoid phrases such as 'gone to sleep' or 'lost' when talking about the person who has died as it can be confusing for children.

Activities to support grieving children

- Books that involve death can open up conversations between you and your child. Please see our website for an up-to-date list of books to support grieving children
- Art and craft activities can be a really helpful way for children to explore and express their emotions in a creative way
- Keeping a journal or writing stories, poems or songs can help children express their feelings
- Making a memory box is a good way to share feelings and good memories.

How can Hospiscare support me?

We recognise that grief is very individual and therefore try and offer as many options for support as we can. Some people will find it helpful to talk to someone while others will want to run a marathon and our website is a good place to start your search (www.hospiscare.co.uk). Alternatively you may prefer to call the team for more information: 01392 688008.

Volunteer-led listening service: Our trained volunteers can provide ongoing supportive listening over the phone.

Volunteer-led social groups in your area: Our trained volunteers run various groups locally, from drop-in teas to film clubs. For more information about what is available in your local area, please contact the Supportive Care Team who will be happy to talk you through what is available. There is also information available on our website. Please be aware that we will follow the latest government guidance in terms of being able to offer face-to-face meetings and some of our groups are offered virtually.

Specialist bereavement services: The multi-disciplinary team that have been supporting you are able to let you know more about our specialist support and will be happy to discuss a referral.

Frequently asked questions

“I feel like I’ve already started grieving and my loved one is still alive.”

David Kessler describes grief as “the death of something”. Sometimes that is a person, sometimes it is a relationship, sometimes it is the “old life” and sometimes it is all of the above. If you need to talk to someone, please call us and we will try and support you.

“But it’s been 6 months/a year/longer. I thought I was ok but I’m really struggling.”

Please call us to see how we can support. Perhaps you would like to know more about our fundraising events, or how to become a volunteer or about a remembrance event you could attend. There is no time limit on when you can reach out for support.

“I had some help initially and thought I was ok. Can I contact Hospiscare again?”

Please do get back in touch. If you have spoken to someone in particular previously, we cannot guarantee that you will be able to speak to this person again. Please call the Supportive Care Team as you might like a different kind of support this time.

Giving consent/how we manage your data

Hospiscare is required to protect your personal information, inform you of how your personal information will be used and allow you to decide if and how your personal information can be shared. Personal information that you provide to Hospiscare in confidence will only be used for the purposes explained to you and to which you have consented.

We may need to share information from your health records with other organisations from which you are also receiving care, such as Social Services or NHS healthcare teams. However, we will not disclose any health information to third parties without your explicit consent unless there are circumstances, such as when the health or safety of others is at risk or where current legislation permits or requires it.

Where there is cause to do this, Hospiscare will always do its best to notify you of this sharing.

If you receive support from a volunteer in our listening service or our specialist bereavement services, we will need to create a record for you on our electronic record keeping system. This information is only shared with those involved in offering your support (e.g. trained Hospiscare volunteers or the Hospiscare clinical team).

Please request to see our Privacy Policy if you require further information and/or speak to a member of the team.

Contacts and websites for additional support

Please be aware that these details were correct at the time of this leaflet's publication.

Local support for adults:

Age UK	www.ageuk.org	
A national organisation supporting older people. Crediton: 01363 775008 Exeter: 01392 202092/455614 Tiverton: 01884 255369 East Devon: 0333 2412340		
Citizens Advice Bureau	www.citizensadviceexeter.org.uk	03444 111444
Free, independent, impartial and confidential advice.		
Cruse Bereavement Care	www.cruse.org.uk	National Helpline: 0808 8081677 Cruse Devon: 0300 330 5466
Adult bereavement support services		
Devon County Council	https://www.devon.gov.uk/help/contact-us/	
For more information about support available in Devon		
Devon Carers	www.devoncarers.org.uk	03456 434 435
Providing advice and support for carers		
FORCE	www.forcecancercharity.co.uk	01392 020021
Providing support for anyone diagnosed with cancer in Exeter, Mid and East Devon.		

National support for adults:

The Bereavement Advice Centre	www.bereavementadvice.org	0800 6349494
Support and advice for people about what to do after a death		
Compassionate Friends	www.tcf.org.uk	0345 123 2304
Bereaved parents offering friendship and understanding to other bereaved parents		
Dying matters	https://www.dyingmatters.org/	
Raising awareness of death, dying and bereavement		
WAY Widowed and Young	www.widowedandyoung.org.uk	
Provides self-help social and support for those widowed up to the age of 50 and their families		
Survivors of Bereavement by Suicide	www.uk-sobs.org.uk	0300 111 5065
For people over 18 bereaved by suicide		

Local support for children and young people:

Balloons	www.balloonscharity.co.uk	01392 826065
Provides pre and post bereavement support for children and young people in Exeter, Mid and East Devon		
Hope again	www.hopeagain.org.uk	0808 808 1677 Devon: 0300 330 5466
Hope Again is the youth website for Cruse Bereavement Care		

National support for children and young people:

Care for the Family	www.careforthefamily.org.uk	02920 810800
Supporting bereaved parents with events, resources and training		
Child Death Helpline	www.childdeathhelpline.org.uk	0800 282 986
For anyone affected by the death of a child		
Child Bereavement Network	http://www.childhoodbereavementnetwork.org.uk/	
The hub for supporting bereaved children		
Child Bereavement UK	www.childbereavementuk.org	0800 028 8840
For children and young people's bereavement support services		
Grief Encounter	www.griefencounter.org.uk	0808 8020111
Supporting bereaved children and their families		
Winston's Wish	www.winstonswish.org	0845 2030405
Support for children and young people after the death of a parent or sibling.		

Hospiscare is a charity

Hospiscare is a local independent charity, caring for people with a terminal illness across Exeter, Mid and East Devon. We receive just 15% of our funding from the government and rely on the generosity of the community we serve to deliver our care.

All donations to Hospiscare are valued. Choosing to donate to Hospiscare after the death of a loved one is a generous and positive act during what is such a difficult time.

Funeral and in memory donations can be made online via our website or on social media. Should you need any help in setting this up digitally, please call the team on 01392 688020 who will give you the support you need.

There are many other ways to support our care in memory of your loved one, from dedicating a leaf on our Memory Tree, donating monthly by direct debit or leaving a gift in your Will. The many different ways you can make a positive impact in memory of your loved one are available on our website or you can call 01392 688020 to chat to a member of the fundraising team.

At this time, our income is greatly reduced. We are doing all we can to continue to provide our vital end-of-life care and support the NHS and so we appreciate all the support shown to us during these uncertain times.

www.hospiscare.co.uk

About Hospiscare

If you live in Exeter, Mid or East Devon, Hospiscare is your local adult hospice charity. Should you or a loved one need care for any type of terminal illness, our professional team of doctors and nurses are here to help. If you would like to make a contribution towards the charity, please visit the website to donate www.hospiscare.co.uk or contact us on 01392 688020. A gift to Hospiscare in your Will helps to ensure the future of the charity in Devon for years to come.

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Tell us about your experience of Hospiscare

Hospiscare welcomes feedback, compliments and complaints and we use them to develop our staff and services.

We know the majority of people have a positive experience, but encourage all your feedback, positive or negative. We investigate complaints thoroughly and treat them as an opportunity to learn and improve our practice.

To tell us about your experience of Hospiscare, please contact:

Director of Clinical Services

Hospiscare, Searle House, Dryden Road, Exeter EX2 5JJ

Phone: 01392 688000

Should you make a complaint, we will send you a letter or email with details of any investigation with an expected timescale where possible. If you wish to see a copy of Hospiscare’s Complaints Policy, please ask. If you are dissatisfied with our response you can contact:

The Parliamentary and Health Service Ombudsman

Millbank Tower, Millbank, London SW1P 4QP

Email: phso.enquiries@ombudsman.org.uk

Customer Helpline Tel: 0345 015 4033

Let us know if you would like the information in this leaflet in a different format; for example in large print or spoken word.

Hospiscare is registered by: Care Quality Commission, 151 Buckingham Palace Road, LONDON SW1W 9SZ www.cqc.org.uk

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www.hospiscare.co.uk

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