

After someone has died during the COVID-19 pandemic

*A practical guide for
relatives and carers*

Because every day matters

www.hospiscare.co.uk

Registered charity no. 297798



Hospiscare
Caring in the heart of Devon

This leaflet offers support for those who have experienced the death of a loved one due to COVID-19. If someone dies of COVID-19 or complications linked to it, it may mean a number of things have happened;

- you may not have been able to be with that person in the lead up to the death
- the death may have happened very quickly
- you may not be able to attend their funeral.

During this uncertain time, people are experiencing an avalanche of experiences; unexpected loss, traumatic loss and social distancing, combined with the worry of losses; loss of one's own job, income, future and other loved ones. These are unprecedented times. There is no roadmap. We are facing situations that we never expected—or wanted—to have.

We recognise every death is tragic and also that no two people are alike in how they will experience grief and, as such, people will find the support they need in different ways.

This booklet has been compiled specifically in light of the outbreak of COVID-19 and the information is also available on our website. If you would like additional copies, please contact the bereavement team.

Contact us

If you would like to speak to the bereavement team, you can contact us on 01392 688008 or bereavement@hospiscare.co.uk (Monday-Friday 9am-4pm). Or for more information visit www.hospiscare.co.uk

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

Contents

	Page
<ul style="list-style-type: none">• What is grief?• The ball and the box• Emotional aspects of grief• Physical aspects of grief• How grief might affect my behaviour• Grieving when you are self-isolating• Grief when you do not get to say goodbye• Alternatives when you cannot hold a funeral• How can I help myself?• What can I read or listen to?• How can I help someone else?• How can I support my children?• Activities to support grieving children• Hospiscare Supportive Services	<p>4 5 6 7 8 9 10 12 14 15 15 16 18 18</p>
Contacts and websites for additional support	
<ul style="list-style-type: none">• Local support for adults• Local support for children and young people• National support for adults• National support for children and young people	<p>19 20 21 22</p>

What is grief?

The death of someone close to you can be an emotionally traumatic experience. In these uncertain and worrying times, it is likely that COVID-19 will have contributed to your recent loss.

Grief is not an illness and it is not a weakness, it is a healthy and necessary response to loss.

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. If it is linked to COVID-19, you may question the treatment they were able to have and whether it was because resources were stretched that your loved one died.

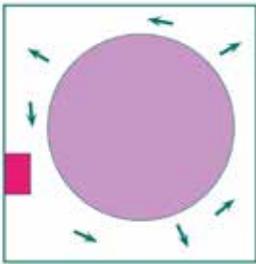
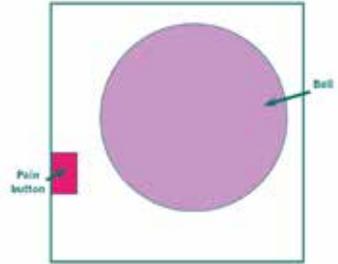
Most bereaved people come through grief with the help of family and friends. At the moment, you may feel more isolated and cut off from those that you would normally turn to for support.

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.

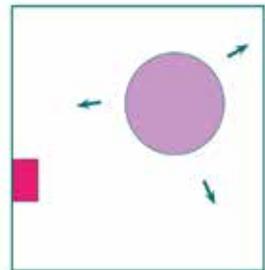
The ball and the box

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. At the moment, people are experiencing a huge amount of change, uncertainty and fear. 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 of control brought on by COVID-19. Death can seem cruel and unfair, especially if hospital resources become overwhelmed and medical staff were forced to make difficult decisions. You may feel the need to blame someone for the injustice of your loss.

Fear: These are unprecedented times and a significant loss can trigger a host of worries and fears for other loved ones and yourself. 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

Given the current situation with COVID-19, most people are even more aware of little changes to their health in case they too are infected with the virus. Some of the symptoms above are 'normal' when grieving, but they could also be symptoms of the virus. You should follow the latest government advice if you suspect you have COVID-19 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

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 consider your options.

Grieving when you are self-isolating

Grief is described as being a lonely experience and this feeling is likely to be heightened due to government restrictions on contact with others.

Your loved one may have been taken into hospital and you couldn't go with them or your loved one may have died at home when you were unable to visit due to self-isolation restrictions. These circumstances can make feelings of loneliness and grief more intense.

Getting support for your grief when you are self-isolating can be difficult. We are trying to put together as much information as we can to support you at this time and we are available to offer telephone support.

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. In both cases, you can feel overwhelmed and your ability to function can be seriously impaired. You may be left feeling extremely bewildered, anxious and life may feel unrecognisable.

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 makes the situation seem more manageable and provides you with some sense of anticipation and preparation. This can become more troublesome if you start to perceive that you might have been responsible for 'missing something'.

Grief symptoms can persist for longer if you have lost someone suddenly or you haven't been able to say goodbye. You can feel a loss of security and confidence in the world because you have had someone snatched away from you without warning.

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 and something positive can come from tragedy.

Alternatives when you cannot hold a funeral

Your loved one might have wanted a funeral service. At present, this is not possible due to Government restrictions. There will be many different reactions to this. Different faiths and religious groups may struggle with not being able to mourn in ways that are in-keeping with traditions and cultural heritage.

When it is not possible to have a service or funeral, you may feel unsettled, guilty or worried that you will not have an opportunity to say goodbye to your loved one. 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.

We do not know how long the restrictions will last so you may want to plan a memorial service that can be arranged for a date in the future.

How can I help myself?

Many people are struggling at the moment with uncertainty and fear. Prioritising self-care at this time 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.

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. Please get in touch with us if you need more information about this.

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

Many of these books are also available as audiobooks or on apps that allow you to listen. 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.

Find out what local services are available:

Many local support groups have been set up to help those in isolation. It might be helpful for you to get that information to support the individual who is bereaved.

The Supportive Care Team may be able to offer further support. Call 01392 688008 for further details.

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 and look to the government websites to get the most up-to-date and appropriate 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.

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 of 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.

Hospiscare supportive services

The Supportive Care Service can provide safe and confidential opportunities for you to share, express and understand your grief. We can do this by providing written information as well as telephone support.

We do not know how long the COVID-19 restrictions will last or what things will be like after this pandemic. We will do our best to support you as much as we can during this time.

Please call the supportive care team if you would like to speak to someone on the phone. 01392 688008

www.Hospiscare.co.uk

Contacts and websites for additional support

Please be aware at the time of going to print, we are unsure what support other agencies are able to offer and how this will change over the next few weeks and months.

Local support for adults:

FORCE	www.forcecancercharity.co.uk	01392 020021
Providing support for anyone diagnosed with cancer in Exeter, Mid and East Devon		
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 Carers	www.devoncarers.org.uk	03456 434 435
Providing support and advice for carers		
Age UK	www.ageuk.org	
A national organisation supporting older people. Creditor: 01363 775008 Exeter: 01392 202092/455614 Tiverton: 01884 255369 East Devon: 0333 2412340		

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 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		

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.

.....

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

.....

SA - 03/2021 Version 1

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

Telephone: 01392 688000 Fax: 01392 495981

www.hospiscare.co.uk

Registered charity no. 297798

