

Bereavement Support

Practical and emotional guidance
for before and after bereavement

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Thank you

to the DEBRA UK members who helped us review this leaflet.

We hope you find this information useful. Please let us know if you have any suggestions for improvements or additional information that would be useful. We'd love to hear from you.

 feedback@debra.org.uk

 debra.org.uk/feedback

 **Feedback, DEBRA, The Capitol Building,
Oldbury, Bracknell, Berkshire, RG12 8FZ**

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DEBRA UK is here to help

We understand how difficult it is to lose a loved one, so we are here to help if you need emotional or practical support.

This leaflet is designed to offer some guidance, practical information, and point you towards different kinds of resources that may help you and your family.

Your DEBRA UK Community Support Manager can be on hand to offer a listening ear when facing a bereavement and when grieving. They can also refer you to other groups for further support in your local area, help make funeral arrangements, work with you to access benefits entitlements (and possibly grants), and assist in creating a remembrance page on our website.

Please contact your Community Support Manager for more information on how you can be supported during this difficult time. You can find details of our full Community Support Team by going to debra.org.uk/eb-support-team

If you don't have a Community Support Manager or you're not sure who it is, please get in touch and we will help however we can.

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 **01344 771961** (option 1)

 **communitysupport@debra.org.uk**

 **debra.org.uk**



Preparing for a death

There are several topics that many people struggle to discuss – death is often one of them. Planning for your own or a loved one’s death can seem scary and might bring up a lot of emotions. However, it is worth remembering that by planning for a death you can help your loved ones know your final wishes and how to be prepared for when the time comes. It can also be helpful in coming to terms with death, particularly when someone has a life-limiting illness.

The specialist EB team are experienced in helping people at this time and will be involved in providing the best level of care with the patient’s wishes considered at all times.

When planning ahead, you may want to consider the following:

- **If you have the option, where would you choose to die?**
– hospital, home, hospice or somewhere else entirely.
- **Who would you like by your side?** – certain family members, friends or other special people in your life.
- **What clothes would you like to be dressed in?** – such as a favourite outfit or sports top.
- **Would you prefer to be cremated or buried?**
- **Do you want to plan your funeral and services?** – for example, consider if you would like to use an undertaker, the kind of coffin, and the type of service.
- **Do you have a faith or cultural traditions you would like to be followed?**
- **Do you want anything special to be read or played at your service?** – this could be songs, hymns, poems or readings.
- **Do you have a preference for mourners to wear?** – for example, black, bright colours, or a specific colour.
- **Do you have a preference for mourners to send flowers or donate to a charity of your choice?**

You might also want to consider making or updating your will to ensure your money and possessions are distributed according to your wishes. Visit the [MoneyHelper](#) website to learn more about why you should make a will. DEBRA UK has also partnered with three suppliers to help members and supporters make a free will. You can find out more at debra.org.uk/make-a-free-will

Making memories

You and your loved ones will no doubt want to make the most of the time left, creating happy memories and where possible carrying out last wishes. Speak to your Community Support Manager to see where DEBRA UK can assist with this. It may be a stay in one of our holiday homes or a special day out. There are also some charities which fund memory making moments and help wishes come true for children who are facing the end of their life. Your Community Support Manager will be able to assist with an application for this.

Practical steps to take after someone dies

1. Report the death to 111/GP/999

If your loved one dies at home, even under regular circumstances, you should contact 111 and your GP so that they can certify the death. If the death was unexpected, you should call 999. If your loved one dies whilst in hospital, you should follow hospital policy.

2. Contact the funeral director (undertaker)

Once you have reported the death, the GP or emergency services will contact an undertaker to transport the person who has died to a local hospital, mortuary or the undertaker's facilities. Most will not charge for this service; as there is an expectation for you to arrange the funeral with them, this service is often included in the funeral costs. Children can sometimes be taken to a hospice and laid to rest in a specialist bereavement suite. This allows family more accessibility and time to say goodbye in a comfortable, nurturing environment.

After you have performed any cultural traditions or ceremonies for the deceased involving the body (e.g. washing), or changed any bandages, the undertaker will transport the person who has died. The undertaker will treat them with dignity and respect, allow you time to say goodbye, and explain what will happen next. The undertaker will always handle your loved one with care, but this is even more essential for patients with a skin condition. A body bag is used to preserve the body and dignity of your loved one.

A post-mortem (also known as an autopsy) may be required if the cause of death is unknown and will be performed by a coroner. This is usually carried out within three days of the referral but may take longer.





3. Register the death

If the cause of death is known, the death should be registered with the Registry Office for the area the person died in within five days (or eight days in Scotland). You will need to have the medical certificate from the GP (or coroner if a post-mortem was performed). Other useful documents include an NHS card, birth certificate, driving licence, council tax bill and marriage/civil partnership certificate.

You will receive an official death certificate once the death has been registered. You could consider requesting multiple copies to help avoid delays or stress. You will need the death certificate for the funeral and it may be requested by other agencies (e.g. banks).

4. Let others know

Knowing who to tell when your loved one has died can be difficult. We recommend making a list of all family members and friends, utility companies, banks and other agencies that will need contacting. Having a list and being able to mark them off one by one will help you to know who you have already contacted, and organise those who should be notified first.



The UK government's Tell Us Once service allows you to notify all government, DVLA and benefits agencies at once.

You can use this by scanning here.

Having to talk to children about the death of a family member, friend or other person of significance in their life comes with a unique set of challenges. Children might need help to understand the situation. Cruse Bereavement Care and Marie Curie have created book lists explaining death and grieving. Your doctor might also have some useful information.

5. Managing belongings and donating equipment

When you are ready you may want to go through your loved one's possessions, such as clothes, jewellery, and furniture. You can see if there is anything you would like to keep, such as items with sentimental value. If you are willing to part with any items, you could consider giving them away to people who might have a fond attachment to them or donating items to a charity shop. Our stores may be able to help by taking unwanted items or collecting furniture (you can find out more at debra.org.uk/furniture-collection).

If you have equipment provided by an Occupational Therapist/your local authority, they will be able to organise recollection of these items when you are ready. The wheelchair service will be able to arrange collection of wheelchairs and scooters provided by them.

For other items such as medication and dressing, please speak to your EB nurse or pharmacist about returning these. Three main charities will collect and redistribute dressings: JacobsWellAppeal, Intercare, and Hospice of Hope. These are based in Birmingham, Leicester and Kent. Your items will either need to be dropped off or posted to them.

Any items that were funded by a DEBRA UK grant do not need to be returned. If you have bought or had DEBRA UK funding for disability equipment that you would like to donate, Scope have some useful information.



6. Plan for the future

At this stage, you may want to do something to honour the deceased's memory. For instance, by either creating a remembrance page, fundraising page, or through another meaningful gesture. This could be making a memory book of photos and letters from friends, planting something special in the garden, creating a patchwork from their clothing, etc. You can turn to page 11 to find out more about creating a remembrance page on our website.

If your loved one had a will, this is also the time to carry out their specific wishes.



If they did not have a will, taking care of their estate is still manageable but will take a bit longer. You can visit the [MoneyHelper](https://www.moneyhelper.co.uk) website for information on what to do in this situation.





Organising a funeral or memorial service

A service to mark the end of someone's life can be handled in a variety of ways. It is unique to the loved one you have lost, and can be organised by you, a relative, or a friend.

People of different faiths and beliefs may have completely different ways to approach this. There are also non-religious and humanist funerals you may want to consider.

It is your decision how involved you would like to be. You can use an undertaker if there is a lot to organise and you need some assistance. It is their job to ensure you have the funeral that is right for your family. There is no obligation to use an undertaker at all, though, so you are entitled to make every decision. Make sure the arrangements are right for you and your family.

Take as long as you need to consider what is right for you.

There is no rush to move the person who has died from your home if you need more time to say goodbye. If a coffin is needed, you can choose whatever material you like. You don't need to organise expensive flowers through an undertaker. Every part of the planning and service is entirely up to you.

To find more information about the kinds of financial support that could be available to you to help with different funeral expenses, continue to page 9.

Financial support

Help with covering funeral costs

The government's funeral funds are available to people on certain benefits and can help cover some of the costs of a funeral. You can find more information about this by going to gov.uk/funeral-payments

All children's funerals are entitled to the Children's Funeral Fund for England (you can find out more at gov.uk/child-funeral-costs). This can help to pay for some of the costs of a funeral for a child under 18 or a baby stillborn after the 24th week of pregnancy. You will be able to discuss this in more detail with an undertaker.

You might also be entitled to Bereavement Support Payment if your spouse or civil partner has died and if they either made National Insurance (NI) contributions for at least 25 weeks or died due to an accident at, or disease caused by, work. Additional criteria and more information about the payment can be found at gov.uk/bereavement-support-payment



Help with everyday expenses

If your child is seriously ill, the **Charlie & Carter Foundation** may be able to help take away the financial stress of everyday living costs – from helping with mortgage payments, rent and utilities, to providing food vouchers and covering other expenses.

Coping with grief

Grief is individual. The way a person dies may have a strong impact on their loved ones. Someone who is grieving may experience some or all the following emotions – shock, denial, anger, fear, guilt and relief.

Grief impacts everyone differently. It is important to try to accept that your emotions are valid, even if your family or friends are experiencing different emotions. Any emotion you are feeling is right for you. There are no set stages which everyone goes through either. There is no timeline we all share.

Take care of yourself as best as you can. It may not be easy, but try to get enough sleep and eat normally. Finding some kind of routine each day, and exercise like short walks, may be helpful as well.

As you deal with your grief, it could help to talk to others – friends, family, healthcare professionals and others around you whom you trust. Some people find that keeping their emotions to themselves for a while is best, at least during the early stages of their grief. Others find that talking to their loved one who has died is helpful; talk about the memories you shared, write letters to them and explore your different emotions.

You may also find comfort in certain environments or activities. This is different for everyone, but could mean spending time with a group of friends, enjoying a hobby, or listening to a piece of music.

Losing a loved one can be incredibly difficult. The way you grieve may change and you might experience strong emotions for a long time. But you are never alone.

Support is always available if you need it

Your DEBRA UK Community Support Manager can help with a referral to bereavement counselling and accessing the support already available in your local area.

For even more information on other charities offering different kinds of bereavement support, go to page 12.

Remembering a loved one

Some people find writing a eulogy (some words) or a poem is helpful during the healing process, so we have created a remembrance area on our website, offering families a chance to celebrate the life of a loved one with EB who has died.

Writing a eulogy to remember your loved one can be intimidating or overwhelming. Take your time and think about what you want to say; write from the heart. A eulogy can take many forms – a formal letter, life story, or remembering happy times. You may want to first write a draft of your eulogy or poem.

You can request a remembrance page by completing some basic details about your loved one and submitting your eulogy or poem. When you are ready, please submit your request by going to debra.org.uk/forms/remembering-a-loved-one

Once submitted, you will not be able to view it immediately; we aim to add your loved one's remembrance page within five working days. Please email us at membership@debra.org.uk using the subject line 'In Memory' and your loved one's name if you would like to include an image or photograph with your submission.

If you require any help with completing the form, please contact us on [01344 77961 \(option 1\)](tel:0134477961) or email us with your request.

Once a remembrance page is live, we will keep them on our website. Remembrance pages can be accessed at any time, and you can also email us to request a change to a page (e.g. to add more information or edit what is shared).



Finding further support

You can always contact your DEBRA UK Community Support Manager for any support you need. There's also a variety of UK charities offering different kinds of bereavement support. Here is a list of some that may be of use to you, whether you are seeking emotional support or additional financial aid.



Child Funeral Charity – a charity offering emotional and financial support to families in England and Wales who have lost a child aged 16 years or younger.



Cruse Bereavement Care – a charity offering face-to-face, phone, email, and online support for anyone who is bereaved.



Child Bereavement UK – a charity helping families rebuild their lives when a child grieves or when a child dies.



Make a Wish – a charity granting wishes for children with critical illnesses, to bring joy to children and their loved ones.



Purple Heart Wishes – a charity funding memory making moments for adults (18-55 years).



Winston's Wish – a charity that supports bereaved children, teenagers, young adults (up to 25), and their parents and carers.



The Good Grief Trust – a charity that hosts pop-up support groups and has a directory of support offered from other agencies across the UK.



Widowed and Young – a charity offering support for people aged 50 and under who have lost a partner. For their members, this includes a 24/7 helpline providing counselling and advice.



01344 771961 (option 1)



communitysupport@debra.org.uk



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THE BUTTERFLY SKIN CHARITY