

Information for parents

England, Northern Ireland, Scotland, Wales

Practical help and support for bereaved parents

The death of a child will always be a distressing time, whatever the circumstances. At this very difficult time certain practical arrangements need to be made, and you may wish to ask friends or relatives to help you. We've set out the practical steps families may need to think about, as well as information about where to go for support.

Where did the death occur

If your child died in a hospital or hospice

a doctor will usually give you a certificate giving the cause of death, and a notice explaining how to register the death with the Registrar of Births, Deaths and Marriages. The hospital or hospice will take care of them until you have arranged to call a funeral director.

If your child died at home or elsewhere

(for example they were in respite care) your GP should be called as soon as possible and asked when they can come and examine your child in order to issue the certificate giving the cause of death. You will also need to decide whether you wish your child's body to be laid out at home or transferred to a funeral parlour – see below for who can help with this. The GP may decide to visit the funeral parlour to issue the certificate.

You will need to register the certificate of death with the Registrar of Births, Deaths and Marriages so you arrange the funeral and make any practical arrangements – see below.

Support from your local hospice

It doesn't matter where your child died, you can still access the support of your local children's hospice.

Parents have said support from their children's hospice has been invaluable at this time.

You can find your local hospice in the telephone directory or on your local authority's website.

Who can help

If your child died at home, in hospital or elsewhere, you can access the support of your local children's hospice. Parents have said support from their local children's hospice has been invaluable at this time.

What help can they give?

Hospices can provide emotional support and counselling, plus information about other support organisations in your area. They also provide practical help, advice and information, for example they may be able to support you with registering the death and provide guidance about funerals. You can find your local hospice in the telephone directory or on your local authority's website.

Hospice services may also be able to come to your home. They can ensure other family members are supported, including siblings, and may help with things like creating memory boxes.

Who else can help?

Your general practitioner (GP), community children's nurse or community paediatrician may also be able to give you information about local bereavement services, support groups, and organisations that offer other support, including practical, emotional and financial help.



Need advice?

Call the Contact
freephone helpline

0808 808 3555

helpline@contact.org.uk

Open Monday to Friday, 9.30am–5pm



Registering the death

You will usually need to register the death within five days – eight days if you live in Scotland. Understandably, parents may feel this will be too much for them, so a friend or relative who was there at the death can do this for you. You can find the address of your nearest register office in the telephone directory or by searching on your local authority website. You may need to book an appointment.

What do you need to take with you?

To register the death you (or the person who goes on your behalf) will need to take the medical certificate of death issued by the doctor. You will need to give the registrar the following information:

- the date and place of death
- your child's full name, address, date and place of birth
- the names, address(es) and occupations of both parents.

If possible, take your child's NHS medical card and birth certificates with you. These aren't essential.

When you have registered the death


The registrar will give you a green certificate to give to the funeral director. This allows the burial or cremation to go ahead.

They should also give you a certified copy of the entry in the register (death certificate). You can use this to tell the Department for Work and Pensions (DWP), or the Social Security Agency, that your child has died. There is a small fee for this.

In some areas your registrar may also provide you with the details of the *Tell Us Once* scheme – this allows a variety of government agencies such as social services, the passport office, and the DWP to be informed about a death at the same time.

If the cause of death is unknown

In these cases a coroner must investigate to find out, for the benefit of bereaved people and for official records how someone has died. This will usually involve holding a post-mortem examination. If it was not possible to find out the cause of death from the post-mortem examination, the coroner has to hold an inquest. An inquest is a public court hearing held by the coroner in order to establish who died and how, when and where the death occurred. More information is at:

 www.gov.uk/government/publications/guide-to-coroner-services-and-coroner-investigations-a-short-guide

Funeral expenses

Many funeral directors will waive basic fees for children's funerals. If you are on a low income you may be eligible for a funeral payment. This is a grant to help meet the costs of a simple funeral, and it doesn't need to be paid back. You may be able to get a funeral payment if you have taken on responsibility for the funeral costs and you are in receipt of one of the following 'qualifying benefits':

- Income Support
- income-based Jobseeker's Allowance
- income-related Employment and Support Allowance
- Pension Credit
- Housing Benefit
- Disability or severe disability element of Working Tax Credit
- Child Tax Credit
- Universal Credit.

You must claim within three months of the funeral, on form SF200, available from the Bereavement Service Helpline, or to download and complete online from GOV.UK

 0345 606 0265

 www.gov.uk

In Northern Ireland you can get a form from your local social security office or download it from:

 www.nidirect.gov.uk

Who can get a funeral payment?

If you are the child's parent, or you were receiving Child Benefit for the child who has passed away, you will normally be able to get a funeral payment (assuming you are on a qualifying benefit).

However, you will be refused if there is another parent – for instance an ex-partner – who is not getting a qualifying benefit. In these circumstances, you will only get a funeral payment if that other parent was 'estranged' from the child. By this, the DWP mean that there was a breakdown in the relationship between that other parent and your child.

If you have taken on responsibility for funeral costs and you are neither the child's parent, nor someone who was getting Child Benefit for them, call our freephone helpline for further advice.

What costs does it cover?

Bear in mind that a funeral payment is only likely to meet some of the funeral costs. Some information on the types of funeral costs that can be met is outlined on the GOV.UK website. More detailed information on the costs met,



and of other potential sources of financial help such as charitable trusts, is available from our freephone helpline.

If your child had any assets then a funeral payment may be recovered from their estate.

Dealing with your employer

If you or your partner work, check your employer's bereavement policies. You may be entitled to a certain amount of time off work to deal with the death of a close family member and to make funeral arrangements. This is often known as compassionate leave, and can be paid or unpaid.

Sorting out your finances

Using the *Tell Us Once* service or the form provided by the register should ensure that any benefits paid in your child's name, such as Disability Living Allowance will stop.

However, as a parent you may also be receiving a number of other benefits in respect of your child in your name, which may either reduce or stop altogether as a result of your child passing away. Unfortunately, neither the *Tell Us Once* service nor the form provided by the registrar will result in a notification being made to those offices that are paying benefit to you, rather than to your child.

As a result, you will need to contact each of the offices paying you these benefits, to tell them about your bereavement. We've outline who you need to contact below, and any time scales you need to be aware of.

Who you need to tell

➤ **Child Benefit, Child Tax Credits and Guardian's Allowance.** These payments can be paid for the first eight weeks after your child died. When you notify the Child Benefit Office of your bereavement you should also ask them to pass on this information to the Tax Credits Office and Guardian's Allowance office if you also receive either of these benefits. If your tax credits award includes help with childcare costs and these reduce following the death of your child, then make sure you also tell the Tax Credits office about the reduction in these costs:

☎ 0300 200 3100
0845 603 2000 in Northern Ireland

Or you can contact the Child Tax Credit office directly:

☎ 0345 300 3900
Guardian's Allowance office
☎ 0300 200 3101

➤ **Carer's Allowance.** If you or your partner were getting Carer's Allowance for your child, this can also be paid for the first eight weeks before stopping. Carer's Allowance will only run on for eight weeks if you were already eligible for it when your child died. If it had already stopped (for example, because your child was in residential care) this won't apply. You need to contact the Carer's Allowance Unit within eight weeks:

☎ 0345 608 4321
0300 123 3356 in Northern Ireland

➤ **Disability Living Allowance.** If you need to contact the Disability Living Allowance (DLA) Unit yourself, (for example the *Tell Us Once* service is unavailable in your area or you don't wish to use paperwork provided by your registrar) call:

☎ 03457 123 456
0300 123 3356 in Northern Ireland

➤ **Motability.** If you were using your DLA mobility to lease or buy a car from the Motability Scheme, you will also need to contact them. You will be given the option of either buying the car outright or returning it:

☎ 0300 456 4566

If you are getting a road tax exemption, then call:

☎ 0300 790 6802.

➤ **Income Support.** If you were getting Income Support as a carer for your child, at the end of eight weeks you will no longer be treated as a carer and your Income Support may stop. Some parents will be able to carry on getting Income Support on other grounds, for example if you are a lone parent of a child aged under five.

If you or your partner are unfit to work (for example because of depression or stress caused by your bereavement), you may be able to get **Employment and Support Allowance** on the basis of your health problems. In order to claim Employment and Support Allowance you will need to get a medical certificate from your GP, known as a 'fit note'. While having a fit note allows your ESA claim to start, within a couple of months the DWP will also put you through their own medical assessment.

If you can't claim Employment and Support Allowance or Income Support and neither you or your partner are working, then after the eight weeks have passed you will need to consider signing on as available for work, and claim Jobseeker's Allowance instead. In some postcode areas you can no longer make a new claim for income-related Employment and Support Allowance or income-based Jobseeker's Allowance, and may need to claim Universal Credit instead.

▶ **Housing Benefit.** Following the death of a child, your Housing Benefit will need to be re-assessed and, depending on your circumstances, you may start to get less help after eight weeks. If the death of your child leads to you being treated as needing less bedrooms under the size criteria rules, any cut in your Housing Benefit resulting from you being treated as having a 'spare' bedroom should be delayed for 12 months. However, this only applies so long as you remain in the same property. If you are claiming Housing Benefit, or help with your council tax or rates, then contact the local authority office paying you this benefit straight away to avoid being overpaid benefit, which you may have to pay back.

▶ **Council Tax.** The loss of your child may affect the amount of help you get towards Council Tax. This will depend on your own particular circumstances. Contact the local council office paying you this benefit straight away to avoid being overpaid benefit, which you may have to pay back.

▶ **Universal Credit.** If you are receiving Universal Credit, then the death of a child will impact on the amount that you receive. However, you continue to receive payments for your child, including any childcare costs, alongside any carer element for looking after them for a temporary period – this is for the remainder of the monthly assessment period in which they passed away, and for the following two months. Depending on your circumstances, the loss of your child may mean that you start to be expected to look for work, as part of continuing to claim Universal Credit. Seek further advice if this applies to you.

Unless you use the *Tell Us Once* service, you will also have to notify any other government departments providing services to your child. For example, this might include social services if you receive a package of support.



Support from Contact

Many parents may have given up work in order to care for their child and the reduction in benefits that follows bereavement can have a major impact on household income. It is important that you seek advice at the earliest possible point about whether there are any other benefits you can claim.

Our freephone helpline has friendly, expert benefits advisers who can help you make sure you're claiming everything you're entitled to.

☎ 0808 808 3555

✉ helpline@contact.org.uk

Child Trust Fund money

If your child was born between 1 September 2002 and 2 January 2011 then a Child Trust Fund account should have been opened for them. When a child with a Child Trust Fund account dies, the money in the account will pass to the person entitled to inherit the child's estate. This is usually the parent(s). No notification is required.

What happens to any equipment my child uses?

You may not be told when any equipment which has been part of your child's life will be taken away, for example, beds or equipment supplied by the NHS. Parents have spoken about how distressing it can be when faced with an unexpected phone call or visit, and that they felt they were not given enough time or respect to grieve before this happens. To help in this situation, contact any equipment suppliers and explain your situation. Try and negotiate a date or time that is best for you. Or you can ask someone else to do this on your behalf, so you can be prepared as far as possible.

Further information

For more information about other practical issues following a death, see:

▶ **Bereavement Advice Centre**

Supports and advises people in the UK on the practical matters they need to do after a death, for example registering a death, arranging a funeral, legal procedures, money and tax issues

☎ 0800 634 94 94

🌐 www.bereavementadvice.org

Or in England and Wales visit:

🌐 www.gov.uk

In Scotland, the Scottish Government produce *What to do after a death in Scotland*, available at

🌐 www.gov.scot

In Northern Ireland, see:

🌐 www.nidirect.gov.uk



Taking care of yourself

This section has been written by parents who have been bereaved and reproduced by kind permission of The Child Death Helpline.

How you might feel

Most people experience a whole range of different emotions; initial feelings may include disbelief, numbness, anger, sadness, guilt, emptiness, maybe even, in some instances, a sense of relief. These feelings may be mixed up together, such that you wonder if you are going mad.

It is very likely that if you have other children they will also have equally strong feelings, and may need a trusted person or friend in whom to confide. If your only child has died you may feel a desperate and bitter sadness, that your parenthood is no longer visible to others. Whether you have other children or not, if you long for another baby, but pregnancy is not possible, or does not occur, this can be an added grief.

Some parents will need to talk about the child's death over again for many months. Some parents will not want to talk about it at all, and will wish to try and 'divert' their feelings, some of the time, into work and hobbies, sometimes to an obsessive extent. It is very common for partners only to have energy for their own grief and be temporarily unable to help each other. This can cause great difficulty, and you may have to acknowledge together that you are expressing your grief in different ways, and respect each other's need to find support in your individual ways.

Having someone listen to the way you feel is almost always helpful. Try not to be afraid to ask for help, outside the family if necessary, especially if you feel that your need to talk is a further 'burden' on relatives and friends. Talking to someone you met perhaps at the hospital may be helpful, or you may find support through the hospital social work department, your GP or health visitor, or child's teacher. You can talk to a local hospice even if your child didn't die at the hospice. There are also specialist voluntary groups and organisations for families whose child has died in particular circumstances. There may also be groups of parents, perhaps in your area, who meet through such organisations to share experience and mutual support.

As months and years go on

The numbness you felt initially will pass in time, but feelings of occasional disbelief, terrible sadness, anger, guilt and emptiness may remain very powerful. Many bereaved parents mention similar experiences:

- the feeling of being on an emotional roller-coaster
- the need to talk about the child constantly
- trying to put on a brave face for others
- the question "Will I ever feel better?"

- the feeling that there is no point in getting up to start the day
- the feeling that no future can be envisaged – to the extent of thoughts of suicide
- the feeling of constant struggle to live hour by hour and day by day.

Don't be afraid to ask for help; talk to someone you trust about the way you feel.

Anniversaries

First anniversaries and anticipating anniversaries will be very hard, and unexpected and poignant feelings and reactions may take you by surprise. Think about how you want to approach these dates. It can be helpful to make a plan and agree how you will remember your son or daughter.

Other people's reaction

Some people, while meaning well, may say very clumsy things. They do not mean to hurt you further, but they can have no idea of the depth of your grief. They may, very tactlessly, try to find something 'positive' to advise, such as focusing attention on other children you may have, or by using unhelpful clichés.

Tell them how you want them to react. If you want them to talk about your child, and to use his or her name, tell them.

Other children


Siblings' needs over months and years to talk about their brother or sister, and what happened, will change as they mature, and you may find that much basic information is required, perhaps over and over again. Any child born into your family in the future should know about his or her brother or sister, and be given the opportunity to ask and talk about him or her.

The future

As you go through the rest of your life, memories and thoughts of your child will always be with you. Nearly everyone needs help in some way, so don't be afraid to ask, no matter how long it is since the death.

The death of your child is the most devastating thing that can happen to you. Surviving it may seem impossible for a very long time. Your life will, of course, never be the same again, but a life worth living is possible.

The organisations on the next page may be of help.



Who can help

If your child has passed away, no matter how long ago, there are organisations you can talk to. They are there to help parents, children and other family members. If your child has, or had, a specific condition, the support group for that condition may be able to offer support and materials. If you've never contacted them before, you can search our online Directory to find their details at

www.contact.org.uk/medicalinformation

> Child Death Helpline

Staffed by bereaved parents, for adults and young people affected by the death of a child however recently or long ago.

☎ 0800 282 986 or 0808 800 6019 if calling from a mobile

www.childdeathhelpline.org.uk

> Child Bereavement UK

Offers support to families who've lost a child and has resources for children and families.

☎ 0800 02 888 40

www.childbereavementuk.org

> The Compassionate Friends

Has local befrienders who listen and share with the bereaved and support bereaved parents, siblings and their immediate families, plus a helpline staffed by bereaved parents.

☎ 0345 123 2304

0288 77 88 016 Northern Ireland

www.tcf.org.uk

> Cruse Bereavement Care

Helps people understand their grief and cope with their loss. Support and offer information and advice for families and young people. They also have face-to-face bereavement support by trained counsellors across the UK.

☎ 0808 808 16 77

www.cruse.org.uk

> The Rainbow Centre

Based in Bristol, provides support to children and their families affected by bereavement in the South West through play, music and art therapy, counselling, massage therapy and group work. They have a reading list for children and one for parents.

☎ 0117 985 3343

www.rainbowcentre.org.uk

> Winston's Wish

Helps bereaved children and young people rebuild their lives after a family death. They offer practical support and guidance to families, professionals, young people and anyone concerned about a grieving child. They have useful downloads, a children's page on the website and a recommended reading list.

☎ 08088 020 021

www.winstonswish.org.uk

> Child Bereavement Network

A hub of resources for professionals working with bereaved families, plus a section on how children grieve.

www.childhoodbereavementnetwork.org.uk

Got a question?

Call the Contact freephone

helpline: 0808 808 3555

helpline@contact.org.uk

www.contact.org.uk



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