

Practical information for when your child has died

Having to make decisions and arrangements at this time is extremely difficult, yet it will be important these decisions are right for you, your child and your family.

Some parents are able to make some of these decisions before their child dies and find a sense of reassurance in doing so. Others find it too difficult to contemplate until after their child's death. This is a personal matter, but please be assured we can help if you want us to.

This information sheet helps explain some of the practical things that will happen and the legal requirements that must happen.

What should I do when my child dies?

Usually there will have been the opportunity for you to have talked through with a member of the care team or another care professional what you would like to happen, what needs to be done and who will be available to support you. This isn't a time to be rushed or feel pressured by others. Your child's death should not prevent you from being the main carer and being involved in their care. Hopefully you will feel able to do whatever you want to do. You may simply want to hold or lie with your child for a while.

You can choose to wash and dress your child. You may want to do this yourself, with family or a friend's help, or you may wish to allow someone else to do this for you.

You can dress your child in your choice of clothes. Your child may have a special toy that you or your family might like to place next to them. Perhaps their brothers or sisters can help with this and be involved.

You may wish to take photographs of your child; this may seem strange but many parents find these helpful later on. Some parents like to have a foot or hand moulds and prints taken. You may like to keep a lock of hair. We can help in creating keepsakes and provide the materials you will need.

What will my child look like?

Your child's body will start to cool gradually. You may be surprised at how cold the body feels after a few hours. They may be extremely pale as the blood in the veins and arteries collects at the lower points of the body. This means they may have a mottled, bruise-like appearance on the lower parts of the body. The body may feel stiff to touch a few hours after death.

Verification and certification of death

Both of these steps are legal requirements but do not usually have to happen immediately your child has died. We will work with other professionals supporting your child and plan who the most appropriate nurse/doctor to verify the death and the most appropriate doctor to complete the Certificate of the Cause of Death.

Occasionally these arrangements cannot be made in advance or it may be necessary to involve the Coroner. If this is likely to happen your lead consultant will talk to you about this in advance.

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If death is unexpected, it is likely the Police will attend and a medical professional from the local Rapid Response Team will be called out to support you. You may want to check the team has contacted us so we can remind you of the ways we can help.

Organ and tissue donation

You or your child may have considered the option of organ or tissue donation – this is sometimes possible, but not always. This can be explored with your child's lead consultant or a donor transplant co-ordinator and we can provide their contact details for you.

Contacting the funeral director

Most funeral directors will do as much or as little as you would like them to. You can, if you wish, arrange everything yourself, but as it's a very difficult time emotionally most parents choose the help of a funeral director.

The funeral director can start making arrangements for the funeral but they will need a 'Certificate of Registration of Death' before the funeral can take place. This certificate will be given to you by the Registrar when you register the death.

Many funeral directors do not make any charge or only a minimal charge for arranging funerals for children and young people.

Registering the death

The death must be reported to the Registrar of Births and Deaths usually in the district where your child died. However, you can register in a different district if your child died at the hospice for example and you have returned home.

If your baby's birth has not been registered, you'll need to register both their birth and death. If your baby has died within a month of being born, the birth and death can be registered at the same time.

The death should be registered within five days, unless there are circumstances preventing this, such as the need to refer to the Coroner.

The Registry Office can be found on the internet or telephone directory under 'Registration of Births, Deaths and Marriages'.

If your baby was born as a stillbirth you should register this within 42 days and you will receive a certificate for burial or cremation.

Most Registry Offices book appointments, while others have a waiting room system. It is advisable to phone in advance to see if you can make an appointment.

If you need to register your child's death quickly due to your culture/faith, there are special arrangements in place to register the death outside normal office hours. The care team can provide more information and help you to do this.

Most deaths involving a child are registered by a parent. However, the death can be registered by someone else who was present at the death or an EACH manager if your child died at the hospice. The Registrar will need the following information from the person registering the death:

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- Your child's full name
- Your child's date and place of birth
- Your child's home address
- The names of their parents, their home addresses and occupations
- The date and place of death
- The completed Medical Certificate of the Cause of Death
- Choice of burial or cremation
- If the death was reported to the Coroner, additional information will be required. Please contact the local Coroner's office for advice
- Information about any benefits you may be receiving
- Name and address of GP.

What will the Registrar give me?

The Certificate for Burial or Cremation

This is a green form and is the certificate the funeral director must have before they can make the final arrangements. It is similar to the Certificate of Cause of Death from the doctor.

The Certificate of Registration of Death

This is a white form (BD8) for the Department of Work and Pensions. This form needs to be filled in and returned to the Department of Work and Pensions, with any benefit books for your child, such as Child Benefit and Disability Living Allowance. It is advisable to take a note of the number on each benefit book you return, along with the date on the first un-cashed order and the amount it was for. This may help if there are any queries later on.

These two main certificates are free. You may wish to keep a copy of the entry made in the register. This is available for a small fee and may be needed if you have bonds or savings in your child's name.

The Registrar will keep the certificate given to you by your doctor.

Planning the funeral

You may want to contact someone from your own faith group for spiritual support and practical advice. You may prefer to contact someone from a non-religious background who could also provide similar support such as the Humanist Society. They may be able to help you decide whether you wish your child to be buried or cremated and what sort of funeral service you want. We can provide information and guidance if you would like us to.

If this person does not know your child well, it will help if they can spend time talking with you about your child. This will enable them to build a picture in their mind of your child's personality and character so that this can be reflected in the service.

Favourite songs, poems and readings can be used in the service, or you may choose to write something of your own. You may like to have an order of service sheet and this can include

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photographs, quotations that have special meaning for you and announcements of thanks to people who have been important in your child's life.

The funeral service can take place at a religious place or a crematorium, but there is no reason why it can't be held in your home or any other suitable venue if that is what you want.

Burials

For some people, a grave in a cemetery or churchyard provides a physical place where you can go to remember someone. It's a peaceful place where you can leave flowers and have quiet thoughts.

Buying a burial plot can be expensive. It is possible to buy either a single plot or one where other members of the family can be buried too. Some cemeteries have a special area just for children. Some have strict rules about the type of headstones allowed, while others are less rigid.

Many churchyards are becoming full, so you may not be able to bury your child where you would wish to. For this reason you need to discuss all the possibilities with the person helping you make the arrangements and with your funeral director, and perhaps visit the graveyard before the service.

This may sound distressing but it will be important to you where your child is buried and you may be less distressed doing this than finding that the grave was not where you wanted it to be.

There are no regulations about burying any belongings or toys with your child.

Cremations

For some, the gardens at a crematorium appeal more than a traditional cemetery, or perhaps there may be a tradition of cremations in the family.

Many types of service are permitted including humanist services and services led by the family or ministers of religion.

You can sometimes extend the normal time allowed at the crematorium if you arrange this in advance, although a double booking would attract a double fee.

There may be restrictions on additional belongings and toys being placed in the coffin (this is not being obstructive but obeying the Clean Air Act).

Afterwards, the ashes will be placed in a box and you can choose whether you want them scattered or buried. You may not know immediately what you want to do with the ashes, and some families keep them in a safe place at home or at the funeral director's while they make this decision.

The burial of ashes can be done in a churchyard by prior arrangement. Ashes can also be buried in an existing family grave. They can be buried or scattered in the crematorium garden where you can usually mark the spot with a plaque or plant. You may choose to scatter the ashes at a place that has special memories for you or your child, or you may wish to keep your child's ashes.

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One of the very hard things you may have to consider is that very small babies will not produce any ashes, and very small children will only produce small amounts of ashes.

Whatever you decide to do, it is advisable to think carefully about how your decisions will affect you in the future.

Financial help for funerals

It is worth asking friends for advice when choosing a funeral director. Some charge very little for a child's funeral. Companies which belong to the National Association of Funeral Directors abide by a code of professional conduct and must give a full written estimate in advance of the service.

If your family is already receiving any of the following benefits, you can apply for help towards the cost of the funeral:

- Income Support
- Job Seeker's Allowance
- Housing Benefit
- Council Tax Benefit
- Working Family Credit
- Disabled Persons Tax Credit.

You can get a funeral payment claim pack from the local Department of Work and Pensions (DWP) office. This contains a SF200 form to give to your funeral director, who will fill it in. You then return this form to the DWP office.

They can give a grant towards the funeral costs, plus payment for doctor's fees, cremation fees or the purchase of a single burial plot and interment fees, if carried out by the local council. Unfortunately you can't claim money for a headstone, which can be very expensive.

What happens to my child's allowances?

You may have been receiving various benefits to help you care for your child. The following benefits continue to be paid for a further eight weeks after the death of your child:

- Child Benefit
- Carer's Allowance
- Dependant's Allowance Component of Income Support or Job Seeker's Allowance.

As all other benefits stop straightaway, you should return all your benefit books to the Department of Work and Pensions. They will then pay you for the extra eight weeks benefit owing. Please be prepared that if you have a car under the Motability Scheme, you'll be contacted to arrange taking the car back very soon after your child's death.

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Post-mortem

A post-mortem is an examination carried out after death by a specialist doctor. There are two main reasons why this may be necessary:

If it is legally required

The Coroner can order a post-mortem if:

- The death is sudden or unexpected
- The cause of death is unknown
- Death occurs during or soon after an operation
- There are suspicious circumstances
- Your child was not seen by a doctor during the 14 days prior to their death.

The doctor will have to inform the Coroner of such cases and the Coroner must then decide whether a post-mortem is necessary. If the Coroner asks for a post-mortem, it can be carried out even if the parents do not want it.

After the post-mortem, the Coroner will issue the Death Certificate.

If you or your doctor wish to know more about your child's illness

This could be to find a diagnosis or to try to understand the illness better, or if genetic investigation is advised – however, it may not provide all the answers. This is not a legal requirement and can only be done with your consent. You would need to talk it over carefully with your doctor so that you feel you have made the right decision.

Many parents worry about how their child will look afterwards. You should not be able to see any signs that your child has had a post-mortem when he or she is fully dressed.

Child Death Overview Panel (CDOP) notification

By law, all children's deaths need to be notified to the CDOP local to the family's home address. This is standard practice for all childhood deaths, whether the death was expected or not. This is done by a form, which is completed by the lead professional involved with your family.

Where can my child stay until the funeral?

The immediate period after the death of your child is a very important time for you to say your goodbyes. It's important to be able to look back and feel that what you did was right and what you wanted at the time.

Each family member may want to say their goodbyes in different ways. They may need time to be alone with the body or have the opportunity to go back several times to see the child to help understand the reality of what has happened.

It is a very individual decision where your child stays before the funeral and there are several choices:

At the funeral director's

Many choose to allow their child's body to be taken to the funeral director's where it can be kept cool until the service. You can go and see your child there as often as you wish.

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At home

Some decide to bring the body back home on the day of the funeral so that the journey to the service can start from there. Others feel it is right for their child to remain at home all the time and the body can be kept cool in a room. The funeral director can advise you on this and we can provide a portable cooling blanket

At the hospice

If your child has died at the hospice then you can choose for them to remain there. If they have died elsewhere, you can arrange with the funeral director for the body to be brought to the hospice, where they can usually remain until the time of the funeral. The hospices have cooling facilities available.

We work with the funeral director, to ensure your child is cared for in the most respectful and dignified way. This may involve placing them in their coffin or transferring them to the funeral director's chapel of rest if it becomes necessary. We will support and guide you in making these decisions.

Wherever you choose for your child to stay, you may decide to have their body preserved by a procedure called embalming. This will involve the funeral director using two small incisions to replace the body's own fluid with a liquid preservative.

Involving brothers and sisters

As parents you know your children best, but we also appreciate that this can be an extremely challenging time and we are here to support you if you would like us to.

Many parents worry about allowing brothers and sisters the opportunity to say their goodbyes. This will be your choice but in our experience, children cope better with the death of their sibling when they are able to do so.

The children will need preparing for what they will see, according to their age and understanding. It can be helpful to tell them the body will be very pale or may appear a little mottled and that it will feel cold. Often they imagine something which is far worse than the reality, and they can be surprised at how little they needed to fear. They may need to touch the child to discover how cold he or she has become, to begin to realise that death has occurred.

They will need someone they know and trust to be with them and answer any questions they may have. They will need reassurance and love and it is much more reassuring for them to be kept within the family, rather than for them to go and stay with someone else, however kindly meant.

What do I tell them?

This can be difficult, but usually if you are honest with children and use words they understand, you will be helping them. They often don't want a lot of information at one time; short explanations and answers will be enough. If you find it too difficult, a close friend or relative might help at this time.

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It is quite usual for a brother or sister to appear to play as normal for a lot of the time. Children cannot sustain their sadness and they need this normality.

It isn't always necessary to hide your tears in an effort to protect them. They sometimes need to see that you are sad and crying, to allow them to do it too. It is advisable to be cautious of saying things like 'dying is just like going to sleep'. This can leave a child very afraid of going to bed and never waking up again. Other explanations that may seem comforting at the time can also give rise to fears. It is better to avoid saying anything that doesn't need to be said or may need to be 'unlearned' at sometime in the future.

Should they go to the funeral?

If you have any doubts about whether brothers or sisters should go to the funeral, it is often easiest to ask them what they would like to do. More often than not they will want to go and feel a part of what is happening, however no child should be forced to attend. It will be helpful and reassuring to explain to them in a way they can understand, what will happen and what they might expect to see at a funeral.

If you have a very young child in the family who is going to attend the service, try to have a relative or friend near you to help look after them if necessary. Older children may like to make suggestions for the service, perhaps choose some music or even write something that can be read aloud. It helps if they can feel included in these preparations and make a contribution in some way.

The funeral

Often those attending the funeral may be unsure of what to do after the service. The person conducting the service can make a short announcement on your behalf, expressing your wishes. He/she can also invite people to join you for refreshments afterwards or inform them that this is for close family only.

Some parents wish to shake hands after the service with those attending. Others cannot do this but wish to know who has attended. If asked, the funeral director will make a list of people as they arrive or leave a card on each seat for them to sign.

You may wish to let those attending the funeral know if you have any requests about what you would like them to wear.

Afterwards

After the funeral the numbness you may have been experiencing will gradually subside and the reality of your loss will become more apparent.

Many people expect to feel a little better each day; but often the reverse happens for quite some time. This can be confusing, frightening and very lonely. You may experience sudden waves of grief and sadness that can be quite overwhelming and frightening, as you feel out of control and have unexpected thoughts.

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There may be times when you need to talk about your thoughts and feelings with someone who will simply listen and be there for you but is not emotionally close to you. Your needs will be personal to you, but we hope that you feel EACH staff are there for you whenever you need us.

Bereavement care

We offer bereavement care in a variety of ways including support for individuals, couples, grandparents, family groups or via one of our support groups.

Our wellbeing team are available to support you through this time and will discuss and agree with you how best to meet your needs. We offer regular contact to families by phone calls, visits to the hospice and home visits. Brothers and sisters can continue to be involved with sibling activities and support at the hospice.

It is important to us that you know we are there for you, but we don't want to intrude. We hope you will feel able to tell us what you want and what you feel comfortable with.

We hold a special memory service at our hospices every year and you will be welcome to join us each time, and for as long into the future as you wish. We will send you an invitation to these events. There is also a memory book at each of the hospices, where you can dedicate an entry to your child by including a photo, poem, writings or messages of your choice.

It is not unusual for parents to contact us again after some months or even a year or two to renew contact and receive support if they're experiencing a particularly difficult time.

How to contact our teams

EACH Milton (Cambridgeshire) 01223 815100; eachmiltonadmin@each.org.uk

EACH Quidenham (Norfolk) 01953 888603; eachquidenhamadmin@each.org.uk

EACH The Treehouse (Suffolk and Essex) 01473 271334; ipswichadmin@each.org.uk

www.each.org.uk/contact-us