



Caring for your child at end of life

A guide for parents and carers

Caring for your child at end of life

A guide for parents and carers

First edition © Together for Short Lives,

October 2019

ISBN: 1 898 447 42X

Author: Lizzie Chambers, Director of Programmes, Together for Short Lives
Editor: Marcella Pinto
Design: Qube Design Associates Ltd

Review group

Helen Bennett: Director of Care, Alexander Devine Children's Hospice
 Francis Edwards: Paediatric Palliative Care Liaison Nurse, Bristol Royal Hospital for Children
 Anne Harris: Director of Care Services, Rainbow Trust Children's Charity
 Abi Warren: Service Support and Development Manager, Together for Short Lives

Acknowledgements

This guide would not have been possible without the support and feedback from parents/carers who commented on the draft and provided their own experiences of the death of their child. With thanks to Cath, David, Di, Gail, Janice, Lorna, Margaret, Sally, Sharon and Vicky. We are also grateful to all professionals who shared their practice experience of caring for a child at the end of life and after death.



When a child's life is expected to be short, there's no time to waste. Together for Short Lives is here to make sure the 49,000 seriously ill children and their families across the UK can make the most of every moment they have together, whether that's for years, months or only hours. We stand alongside families, supporting them to make sure they get the vital care and help that they need.

Registered charity in England and Wales (1144022) and a company limited by guarantee (7783702).

Together for Short Lives

New Bond House, Bond Street, Bristol BS2 9AG

T: 0117 989 7820

info@togetherforshortlives.org.uk

www.togetherforshortlives.org.uk

Caring for a child at end of life: A guide for parents and carers has been made possible by funding from Children with Cancer UK.



Disclaimer: While great care has been taken care to ensure that the contents of this document are correct and up to date at the time of publishing, neither its authors nor its publishers can guarantee its correctness and completeness. The information contained in the document is intended for general use only and users should take appropriate steps to verify such information and as necessary obtain legal and/or professional advice. None of the authors or the publishers accept responsibility for any loss, damage or expense resulting from the use of this information and no actions should be taken in reliance on it without relevant professional advice.

Note: Throughout this document the term 'child' is used to mean child, babies and young people. The term 'family' acknowledges the diverse relationships within a family including the role of the carer whoever that may be.

Foreword

In many ways, I wish I wasn't a mother qualified to write about the death of a child.

And even more so, I wish you didn't need to read this. Let me tell you what I've learnt from the death of my beautiful triplet daughter, Essie, who died aged 18 months and was life limited from 11 days old.

Please cherish those moments you have with your child. Even on the worst days when the whole situation might seem completely overwhelming, take a moment – even if it's just for a second – to hold them, to smell their hair, to tell them you love them as when your child is gone you will have memories. With Essie, we lived one minute at a time or one hour at a time or one day at a time; whatever we needed to do, we did. We focused on life and making memories. We took so many photos and so many videos. These memories are priceless and precious.



Take time to plan and think through what you want to happen, and how. Essie had an Advanced Care Plan (ACP) in place, which was her 'living will' and this included our holistic wishes. The main point we kept telling everyone was Essie wanted to be around her family to help make memories for her triplet brother and sister (and us too), which was the first point in her ACP, and if we could keep her out of hospital, we did.

You will have good days and you will have bad days. Never be afraid to fight and challenge what you think is right for your child. You are the best medical professional that your child has.

End of life isn't always end of life and a life-limiting condition is not just about end of life care. Essie went through five end of life episodes between March 2017 and 13 August 2017, which is the date she died. I never knew that a doctor could pronounce end of life and a child wouldn't always die. I really struggled with the hospital transfer to the children's hospice for Essie's end of life in March 2017, as she didn't die immediately. We were told by doctors that she was very unwell and weak and wouldn't survive 24 hours, but she did. I know now that end of life is only end of life if a child decides it is; children fight end of life so hard, as they want to keep making memories.

I want to tell you that it's ok to feel relieved when your child dies. We were told Essie's life limiting prognosis when she was in NICU and 11 days old. This was when our world fell apart. For the next 18 months, we were dealing with anticipatory grief. The complexity of grief can't be underestimated, and it is an all-consuming and powerful emotion. I had never even heard the term 'anticipatory grief' until our first counselling session post Essie's death. Your grief journey will be yours and yours alone. It won't be the same as anyone else's, so don't compare.

This might sound weird, but don't fear death. We took Essie's triplet brother and sister into her room when she had died to say goodbye. We didn't use words such as goodbye, but we gave them the choice to see her. They threw themselves on top of Essie in her special bed and started kissing her. We took photos of this moment and they are honestly amongst my favourite photos of the three kids together. Please consider doing this and ignore whatever remarks people might say, as you might need these photos one day or most days.

Essie went to Chestnut Tree House, her children's hospice, from 13 weeks old. We were always adamant that she was not going to die at home, but after the third end of life episode we changed our mind. Essie wanted to stay at home until she died, so this is what happened. We asked to have a police mark put on our house, as we'd chosen to have her end of life at home.

And we did something else that most people are surprised to hear. When Essie died and we'd changed her, removed her tubes and got her brother and sister to say goodbye (in their own special way), we drove her to her children's hospice ourselves. I was sat in the backseat of our car holding Essie in my arms and we talked and sang to her the whole drive to Chestnut Tree House. Do whatever feels right, but you don't have to wait for a funeral director.

There's so much more that I want to tell you about the death of a child, but I will finish by saying this: you will be ok, you will be a different person, but you will be ok. I'm now two years into my life after loss journey and my goodness the tears can flow so easily when I talk about Essie, but I also smile and laugh and live. I don't cry every day, my grief nightmares are becoming fewer and fewer, and I've found new friends who 'get it' as they've been through their own loss journey too.

I speak Essie's name freely and will try to correct people who don't speak it for fear of upsetting us. We also write Essie's name (or a little star) in cards. We buy her a birthday card and Essie has her own birthday cake. I am always going to be a Mummy to triplets. The world might see twins now, but I correct anyone that calls Roman and Eva twins. This is not who they are, and I will never apologise for telling it how it is.

Go gently and you will be ok.

Lorna

Lorna writes about her journey of life after loss on social media (@mummylovesessie)

Contents

NICE Quality Statements for End of Life Care for Children

Introduction

Section 1: Care before death

Introduction	10
What is children's palliative care?	10
How do I cope with the knowledge that my child will die?	10
How do I talk to my child/children about death?	10
How can I be sure my religious beliefs will be respected?	11
Who makes the difficult decisions about end of life care?	11
What is an Advance Care Plan?	11
Who do I talk to about organ and tissue donation?	12
Who can I talk to about managing my child's pain and symptoms?	13
What is a digital legacy and how do I manage it?	13
How can I create special memories of my child?	14

Section 2: Care at the time of death

Introduction	16
Do I have choice over where my child dies?	16
Can other members of my family be there?	16
How do I know if my child is nearing death?	16
What can I do when I think my child is near death?	17
What happens if I am not there when my child dies?	17
Are there any official processes immediately after a child has died?	18
What is verification of death?	18



NICE Quality Statements

Section 3: Care after death

Introduction	20
What should I say to my other children?	20
Can I care for my child's body after they have died?	20
What support is there for me?	20
Will my religious or cultural customs be respected?	21
What will happen to my child's body after death?	21
What is embalming?	22
Where can my child's body stay until the funeral?	22
How do I transport my child's body?	23
What is the role of the coroner?	23
When is a post-mortem required?	24
What is certification of death?	24
What is the Child Death Overview Panel (CDOP) process in England?	24
Do I need to register my child's death?	24
What happens to benefits after a child has died?	25
What does a funeral director do?	26
What if my child's body needs to be repatriated?	26
What are my options for burial or cremation?	27
How do I go about planning for my child's funeral service?	28

Section 4: Bereavement support for you and your family

Introduction	30
What bereavement support is available?	30
Can I get support for my other children?	30
How do I tell people that my child has died?	30
Bereavement support organisations	31

Section 5: Glossary of Terms

32



Statement 1: Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Statement 2: Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.

Statement 3: Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.

Statement 4: Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.

Statement 5: Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.

Statement 6: Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

Introduction

Every family's experience is unique, but the death of a child is always devastating. Some families may have years of caring for a child with a life-limiting illness, some may have only days or hours together when they find out that their child is approaching death. Whatever your individual situation, you will feel that your world is falling apart and intense grief for the impending loss of your beloved son or daughter.

We hope that this guide will provide practical information to support you at this most difficult of times. It aims to answer some of the questions that you might have, with some reflections from families on their own experience of losing a child. It also sets out what you should expect from children's palliative care services with useful links to further sources of information and support.



We have written this guide for members of your care team to share with you, to enable you to talk to your family and to your care team about yours and your child's wishes, so that you can make informed choices and get the help and support that you need at this time. You might find it helpful to read through the whole booklet so that you can feel ready and prepared in advance.

"Preparing yourself for when your child may not recover from their illness is lonely and heart-breaking. To have a resource that guides you through what to expect and where to go for help means you are not alone. You can prepare in your own time and at your own pace. It also gives you permission to think the unthinkable."

Section 1 Care before death

Introduction

Having information about what to expect and knowing where to go for support can help you to share precious time together with your child towards the end of their life. Your care team should provide appropriate information to enable you to make decisions for your family. You may have been supported by a children's palliative care or hospice team for a while or you may at this point be introduced to a children's palliative care team for the first time. Every parent carer is an individual and will deal differently with their child's prognosis – so you should be supported in whatever way works best for you.

What is children's palliative care?

Children's palliative care is an approach to care which is focussed on enhancing quality of life, when a cure is not possible. It is about managing a child's pain and symptoms, but also about supporting the whole family by providing emotional, spiritual and practical support throughout their illness. Children's palliative care can be provided by a range of different professionals at home, in hospital or in a children's hospice. Sometimes a dedicated children's palliative care team will support you alongside the team that has been supporting you throughout your child's illness or their stay in intensive care. A palliative care team is sometimes also called a symptom management team as they have specialist knowledge in treating pain and symptoms.

How do I cope with the knowledge that my child will die?

Grief is very complex and you will be living with anticipatory grief from the point where your child is given a prognosis of a life-limiting or life-threatening condition. You should be able to access bereavement support throughout the course of your child's illness.

“Living day to day with a life-limited child you tend not to want to read or plan for their future death, but instead live each day to the full.”

How do I talk to my child/children about death?

Try to talk honestly with your affected child or with your other children and be aware of their understanding of illness and death. It can help to use the following tips in talking with children:

- Talk with them, not about them.
- Use language they will understand, not euphemisms.
- Speak in the child's language (recognising body language and play language).
- Don't rush them and don't interrupt, allow them to talk and respond.
- Listen attentively.

It can be helpful to talk to siblings weeks, months and years after the death of their brother and sister about how they are feeling. Their perception of what has happened and the impact on them is likely to change as they grow up.

How can I be sure my religious beliefs will be respected?

Part of what makes people human is the need to make sense of life and find meaning in death. For many this is understood through spirituality, faith and cultural values. All health and social care professionals should work to support your individual needs as your child approaches death.

Who makes the difficult decisions about end of life care?

Children's palliative care may involve making difficult decisions. Care professionals should understand that your views and understanding are at the centre of all decision-making. They should also be aware that decision-making about a child's end of life care is fluid – families often change their minds – so don't feel rushed into decisions that you are not sure about. Your child's needs and best interests should be assessed, and a plan of care should be discussed and developed with you and your child, so that your beliefs and choices are included.

Useful resource

A Parent's Guide: Making Critical Care Choices for Your Child, Together for Short Lives, 2014.

What is an Advance Care Plan?

Advance Care Planning (ACP) is a process of discussion between members of your family and your care team. It can enable decisions to be made and documented relating to you and your child's wishes and preferences on a whole range of issues, for example about preferred place of care and how you want to make memories together, as well as decisions about end of life care. An ACP should include your holistic wishes for your child while they are living as well as plans for their death. All conversations surrounding Advance Care Planning should happen at the most appropriate time for you. You are free to change your mind at any time, so any decisions made should be reviewed on a regular basis. You might want to think about the things you are worried about and the kind of questions that you would like to ask your care team.

Questions to think about when developing an Advance Care Plan

- What care is available and when and where can it be provided (eg is it 24 hours a day, 7 days a week, at home?)
- Who will be there out of hours to care for your child?
- What sort of steps do you want the care team to take if your child needs resuscitating or if they suddenly deteriorate?
- Will it be possible to withdraw invasive treatments and equipment and allow your child a more natural death?
- What are your views on organ and tissue donation? Do you need more information about this?
- Who will ensure that your child's pain and symptoms are well managed?
- Who do you want to be there at the time of your child's death?
- Who will look after your other children?
- Who will call family, friends, school etc?
- Where do you want your children to be cared for at the time of death, and after death?
- What kind of ceremony or ceremonies would you like?
- Does your child wish to make a will?
- Have you thought about your child's digital legacy?

Who do I talk to about organ and tissue donation?

Many families understandably do not wish to consider organ or tissue donation, but for some this may be something that you want to explore. Your care team should let you know as early as possible whether it will be possible for your child to donate organs and/or tissue, given your child's individual condition. Children with certain genetic conditions or who have had cancer treatment may still be able to donate tissue or corneas.

If you would like to have a more in-depth discussion about organ donation, further information and support are available through a specialist nurse for organ donation within your local trust or nationally at www.organdonation.nhs.uk. If you do choose organ or tissue donation, it is worth noting that this may influence where your child dies because this will need to happen very quickly.

Did you know?

After 2020 over 18s will be presumed to have consented to organ donation unless they have opted out. Those who lack mental capacity are a protected group so are automatically opted out. www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-england/

Who can I talk to about managing my child's pain and symptoms?

You may find a specialist palliative care team (sometimes called a symptom management team) helpful in providing additional advice and support about managing your child's pain and other symptoms and developing a plan for this. Effective symptom management for children is essential to ensure their comfort and enhance their quality of life. Alongside medications, there may be a range of approaches to manage other sorts of pain (physical, psychological, social and spiritual) for both your child and your family. You should be given contact details of professionals who are available to support you, in and out of hours.

What is a digital legacy and how do I manage it?

Children and young people spend a huge amount of time online, using social media, gaming, and sharing photos. It is important to think about how this will be managed after they die, enabling these accounts to be closed down or to be used to celebrate their life. It can be helpful to have talked to them about all of their online activity and digital assets, for example asking them to share their passwords for email addresses, social media accounts, blogs or YouTube channels so that you can manage these after they have died. It can be helpful to start this digital legacy planning early in case your child dies suddenly.

Useful resource

The Digital Legacy Association has a wealth of information about how to manage digital legacies and digital assets: <https://digitallegacyassociation.org>



How can I create special memories of my child?

It can be a comfort to collect mementoes of your child to keep as a special reminder of them for you and for their siblings. There are many different ways to do this, for example:

- taking photos
- taking a small lock of hair
- making handprints and footprints or hand and foot sculptures
- keeping special toys, jewellery or ribbons
- painting something together
- putting together a memory box
- writing in a book of remembrance at the hospice or hospital
- placing something in a garden of remembrance or other special place

Useful resources

- Sacha Langton-Gilks, *Follow the Child: Planning and Having the Best End-of-Life Care for Your Child*, 2018
- Five Things for Life, Death, Whatever: A blog by Lorna Cobbett
www.lifedeathwhatever.com/five-things-blog/five-things-ive-learnt-from-facing-the-end-of-life-with-essie-my-life-limited-triplet-daughter-by-lorna-cobbett

“We took Essie’s triplet brother and sister into her room when she died to say goodbye. We didn’t do anything or use words such as ‘goodbye’, but we gave them the choice to see her. They threw themselves on top of Essie and kissed her. We took photos and they are very precious.”

Section 2 Care at the time of death

Introduction

It can be an intensely emotional time waiting for your child to reach the point of death and you are likely to experience an overwhelming sense of grief as your child dies. Your care team should support your child to have the best possible care until the end and to help you have time together peacefully as a family.

Do I have choice over where my child dies?

Care can be provided across different settings to enable your child to be cared for and to die in your preferred place, whether this is at home, in a hospice or in hospital. You should be able to choose your child's place of death and where possible should be helped to achieve this, recognising that sometimes it is not possible if services are not available or depending on the treatment that your child is having. You are free to change your mind at any time and your care team should recognise this and support you to achieve your wishes.

Can other members of my family be there?

You are also free to decide who is with you as your child dies. You might want to have your other children, your parents or other family members there with you.

How do I know my child is nearing death?

It can be difficult to know when your child is approaching death as their symptoms may fluctuate, but it is likely that you will notice that they are getting more sleepy, that they are slipping in and out of consciousness, or that their breathing is changing and their skin becoming cooler. Dying is a process and you may notice that your child's breathing stops and then starts again. Many children will have repeated 'end of life' episodes where it appears that they are about to die and they then rally.

"The doctors told me she wouldn't survive 24 hours, but she did. We had five end of life episodes with Essie. End of life is only end of life if a child decides it is."

What can I do when I think my child is near death?

You can help your child by 'giving permission' for them to die, not necessarily through words, but by creating a calm and peaceful environment, with lowered lights, gentle music and just being there to soothe them. If you are at home and feel that you need support, you can call your care team and speak to someone on the phone or it might be possible for a member of the team to visit you. You might have a dedicated children's community palliative care team or hospice which can provide 24-hour care at home when a child is at end of life. They will support your child to feel comfortable, although this may mean that they are no longer awake.

"During the periods when he became very ill and looked as if he might be failing, we told him that we were close by, that we were staying with him to look after him and there was no need to be afraid because we were all by his side. This made a huge difference and afterwards he was peaceful and settled."

What happens if I am not there when my child dies?

Sometimes it is not possible for you to be there when your child dies. Some parents may choose not to be there when their child dies, for others the death may be sudden and unexpected. You should not feel guilty about this, whether it's a choice or not. It can help to think in advance about how you want to be informed about your child's death if you will not be there and to record your wishes about things like whether or not you want your child to be moved, how you want them to be dressed etc. Be reassured that staff will care for your child in your absence.



Are there any official processes straight after a child has died?

The process is different, depending on whether your child's death is expected or unexpected. If it is expected that your child will die from their condition, this should have been clearly documented in your child's records and no further procedures should be needed. However, it is still not always easy to anticipate when, or in what manner they will die from their condition. If the death is sudden it will need to be reported to the doctor so that an investigation can be arranged into the exact cause of death and any contributory factors. National and local policies will outline procedures for the Sudden Unexpected Death of Infants and Children (SUDI). If there has been no explicit advance decision for a 'do not resuscitate' order it will be presumed that attempts will be made to resuscitate the child.

"You can put a police mark on your house, if you choose to have end of life at home, otherwise the police will quickly have to attend all child deaths."

What is verification of death?

This is the process of professionally verifying that your child's life has ended. There is no rush to do this if the child's death is expected. Verification of death is separate from the certification process (certifying the cause of death) and can be performed either by a medical practitioner or by another qualified professional, such as a nurse. All deaths must be verified, including for babies born after 24 weeks.



Section 3 Care after death

Introduction

In the days following the death of your child, you and your family will experience a variety of emotions. You are likely to feel overwhelmed with grief and exhaustion. At the same time you will be planning for your child's funeral or other ceremony. It's important that you feel supported to take things at your own pace and to know that you can do as much or as little of this planning as you want.

What should I say to my other children?

Grief will affect children in many ways depending on their age, experience and relationships within the family. Honest and meaningful communication is important. Letting siblings know what is going on and actively involving them in what is happening can help them to cope better. All conversations should take account of their individual needs, recognising their developmental stage and capacity to understand, but it is usually best to be very clear and honest, saying that their brother or sister has died so that they don't misunderstand what you are saying. Consider past conversations you may have had with your children, any religious or cultural beliefs you hold as a family and words used in your family that your children may understand.

Can I care for my child's body after they have died?

Once an expected death has been verified, you can be as involved in the personal care of your child as you wish. Whether you are in hospital, at home or in a hospice you should be supported to spend time with your child and care for them as you would like. Your care team can help to remove medical equipment and dressings if you wish. You can brush their hair, choose an outfit for them and place a favourite toy with them, but do check with your care team first about washing your child's body. It is a good idea to keep the funeral outfit back until the time of the funeral so that it does not get spoiled due to any fluid leakage. Your child's body will need to be cooled fairly quickly, but you will be able to spend some time cuddling them.

What support is there for me?

It's good to talk to family and friends about what you are going through, but sometimes you might feel like they just don't 'get it', as they have not been through the same experience. You might find it helpful to talk to someone who is not so emotionally involved and who you can be confident won't judge you. A spiritual care team or chaplaincy service should be available at most hospitals and hospices and they can link you with local services if you are caring for your child at home. Other members of a children's palliative care or hospice team are also experienced at talking with grieving parents.

"It's ok to feel relieved when your child dies. We were told Essie's life-limiting prognosis when she was 11 days old. This was when our world fell apart. For the next 18 months we were dealing with anticipatory grief."

Useful resource

This factsheet explains the support that can be provided by a spiritual care team:

www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/spiritual-religious-cultural-wishes/

Will my religious or cultural customs be respected?

Children's hospice and palliative care services should all have experience of supporting families from all faiths and in providing care that is culturally appropriate to them and which respects the rituals that are important for each individual family.

"The official day for a burial in Ireland is the third day and there is traditionally a two-night wake to allow time for everyone to come and visit at the house. This meant that the funeral would be on a Sunday. After some discussion, this was accepted by the Minister and undertaker."

What will happen to my child's body after death?

You can talk to your care team and with the Funeral Director or mortuary staff about what will happen to your child's body after they have died so that you know what to expect. If at any stage the condition of their body deteriorates significantly, it may be necessary to place them in a coffin or take them to the funeral directors. The changes to the body that you can expect are:

Algor mortis: After the heart stops beating the body immediately starts to become cold. This phase is known as algor mortis or the 'death chill'. The outer body can chill within two hours but it may take up to eight hours for the centre of the body to cool, depending on the size of the child.

Changes to the eyes: The eyes may become sunken in appearance and if the child's eyes remain open after death, they cannot naturally be closed. An undertaker can be asked to keep the eyes closed.

Pallor and loss of skin elasticity: The skin will become pale and may also become dry. Moisturiser can be applied to the face and body, and lip balm is helpful for keeping the lips moist. Skin can become fragile and there is a possibility of it breaking down if you are stroking your child.

Lividity: Lividity or livor mortis is the dark purple discolouration of the skin which becomes apparent within half an hour of death as dull red patches or blotches. Lividity is more noticeable in some bodies than others.

Rigor mortis: Death usually leads to a short period in which the muscles are relaxed, followed by muscle stiffening known as rigor mortis. Rigor mortis can be apparent within three to four hours of death but will disappear 36-48 hours after death.

Bleeding: There may be bleeding, for example from the nose. If the bleeding can't be stopped the child's body may need to be transferred to the funeral directors.

Leakage of bodily fluids: A small amount of fluid may leak from the nose or mouth after a child has died. Urinary and faecal leakage are also common and a pad may be used to deal with this. If your child has nasogastric or other tubes removed after death it's also possible that this could cause leakage.

Prosthesis: Your child may have a prosthesis in place and your care team should discuss with you if these are to be removed.

What is embalming?

This is the process of temporarily preserving the body. It is a very individual choice and your funeral director or care team can help you think about whether this is something that you would like to consider. To be most effective it should be carried out sooner rather than later. It must be carried out at the funeral directors' premises and there is normally a basic cost. Embalming cannot take place until the coroner has completed enquiries and the death is registered. Embalming is likely to be appropriate where there may be additional or accelerated changes to the body because of chemotherapy or other treatments, or where disease has affected the condition of the body at the time of death. A burial at a natural burial site will not be permitted if the child has been embalmed.

Where can my child's body stay until the funeral?

If your child dies in hospital, they will be kept in a cooling facility within the hospital. There may be a special room nearby where you can spend time with them. You may choose to take your child home from hospital or transfer them to a children's hospice cool room where they can stay until their funeral or before being transferred to a funeral director.

If you choose to keep your child at home and this is going to be for longer than 4-6 hours, you may be able to access an air-conditioning unit or cooling blanket from a local children's hospice or your hospital or community palliative care team. When using a portable unit or cooling mattress seek advice about how to best position the unit in the room, keep all windows closed and turn off radiators. It is still possible to keep your child at home if you don't have access to a cooling unit or blanket.

How do I transport my child's body?

It is helpful if you have discussed beforehand with your care team where you would like your child to be cared for after death so that transport arrangements can be made. If you wish to move your child to a mortuary, funeral directors or cool room at a children's hospice there is no rush, but usually it's considered good practice to transfer a child within four to six hours of death. Before a child is moved, verification of death must have taken place and ideally also certification of death should be completed. If moving a child before certification of death you will need permission from the coroner or procurator fiscal. It is possible for you to transport your child yourself, but do talk to your care team about this so they can make the necessary arrangements with local services.

"We moved Essie ourselves to our children's hospice. I held her in the backseat of our car and we drove her to the hospice. All we did was ask our community children's nurse to call the police and notify them of our car registration. You don't have to wait for a funeral director."

What is the role of the coroner?

Some deaths require notification to the coroner (called the Procurator Fiscal in Scotland) before the death can be registered. They have a duty to investigate certain types of deaths, such as:

- when the cause of death is unknown
- when the death is due to an accident
- where the circumstances are suspicious
- when deaths are sudden, unexpected or unexplained

When a child is referred the coroner or Procurator Fiscal will decide if further investigations are necessary. They may decide that a Medical Certificate of Cause of Death (MCCD) can be issued once the cause of death has been agreed. Alternatively, they may decide there is a need for further investigation in the form of a post-mortem and/or a full inquest.

When is a post-mortem required?

Post-mortems are a legal requirement for any sudden death when the cause is not apparent. As a parent, you can also request a post-mortem examination if you want to find out more about your child's cause of death, for example if it was your first child and they didn't have a diagnosis or if they died in the neonatal unit. It can be a comfort to find out the cause of death for your own child, but also to know that you have helped find answers for other families in the future.

Post-mortems are undertaken by a pathologist who is a medical practitioner. Following the post-mortem your child may be taken to the funeral director to care for their body. Parent requests for post-mortems are not always granted, so this is something to be aware of.

What is certification of death?

The law requires that a medical practitioner certifies the cause of death by completing a 'Medical Certification of Cause of Death' (MCCD). This includes a statement of the cause of death, the date the child died, the date the child was last seen alive and whether they have seen the body after death. If the medical practitioner is unable to establish cause of death, then the case must be referred to the coroner or procurator fiscal. The MCCD is required to register the death of all children, even babies born at 24 weeks.

What is the Child Death Overview Panel (CDOP) Process in England?

The CDOP is a local multi-agency panel which reviews the deaths of all children in their area in England. The overview panel reviews all child deaths by gathering information, identifying any patterns and trends, and making recommendations for improving care and outcomes in the future. For children with life-limiting conditions, there is a special supplementary form that should be completed by the person or organisation providing care towards the end of life. You should be allocated a lead health professional to act as a single point of contact to guide you through this.

Useful resource

A useful guide is published for parents and carers explaining the child death review process: www.england.nhs.uk/publication/learning-from-deaths-information-for-families/

Do I need to register my child's death?

Your child's death will need to be registered at a register office closest to where they died, so that their death certificate can be issued and in order for their funeral to take place. The registration needs to happen within five working days of their death (8 days in Scotland). The registration can be done by someone else if you do not want to do this yourself. This could be

another family member, someone who was present at the death or the person taking care of the funeral arrangements. Registration of death can only take place if the coroner has released the body and all enquiries are complete.

The following are needed to register a death

- The child's full name, date and place of birth and home address.
- The names of the parents, their home addresses and occupations.
- The date and place of death.
- The completed medical certificate of cause of death (not needed if there has been a post-mortem).
- An NHS medical card (if possible).
- The child/young person's birth certificate.
- If the death has been reported to the coroner or procurator fiscal, additional information will be required. Advice can be sought from your local coroner.
- Information about any benefits your family receives.

Once the death has been registered the registrar will issue a Certificate for Burial or Cremation, known as the 'green form' (England and Wales), form 14 (Scotland) or form GRO 21 (Northern Ireland). This must be passed onto the funeral director so that the funeral can take place. In addition, a Certificate of Registration of Death, commonly called a death certificate (form BD8 in England and Wales or form 36 in Northern Ireland) is issued for social security purposes.

What happens to benefits after a child has died?

There is a Tell Us Once service which means that you only have to call one number to inform all benefits agencies that your child has died. Please note that this service is not available in Northern Ireland and in a small number of English counties. If you have a mobility car, this will be collected very shortly after your child has died.

Useful resource

Tell Us Once is a service that lets you report a death to most government organisations in one go: www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once

“The day after my daughter died I sat and individually phoned child tax credits, child benefit etc to inform them. If I had been aware that there is a ‘grace period’ and one number to call that sorts everything I wouldn’t have put myself through all of that at that precise moment. I was terrified of being ‘overpaid’ benefits.”

What does a funeral director do?

Funeral directors are highly skilled and can offer support in many areas following the death of a child. A funeral director, if you choose to use one, can help with all the practical arrangements for your child’s funeral, arranging transport, completing paperwork as well as providing emotional support. Many offer their basic services free of charge to families when a child dies under the age of 16. This generally includes costs of organising the funeral and the coffin, but there is likely to be a charge for cars, flowers and extra services. Some families choose not to use a funeral director and prefer to make their own burial or cremation arrangements.

Useful organisation

The National Association of Funeral Directors <https://nafd.org.uk> provides good advice and lists funeral directors locally. Funeral directors should be licensed with the British Institute of Funeral Directors.

What if my child’s body needs to be repatriated?

When moving a body out of the country you will need to obtain an ‘out of country’ form from the registrar or coroner. The form must be handed to the coroner with the certificate for burial or cremation already issued. The coroner will acknowledge receipt of the notice and let you know when the body can be moved. This is usually four days from when the notice was received, although in urgent situations it may be possible to speed things up. There can be significant cost associated with repatriation, so the earlier that you can discuss this with your care team the better. There is no restriction on moving bodies within England and Wales.

What are my options for cremation or burial?

Cremation

You may choose to have your child’s body cremated and this can be followed by a ceremony to scatter their ashes in a place which is significant or sacred to your family. You will need to complete some forms in order to have a cremation:

- An application for cremation form signed by the next of kin or executor.
- Two cremation forms: A medical certificate completed by the medical practitioner who was treating the child during their last illness, and a confirmatory medical certificate completed by a second medical practitioner.
- A certificate signed by the medical referee at the crematorium to authorise cremation.

Burial

A burial can take place in a churchyard, a local authority cemetery or a private cemetery. Burials can also take place on private land, or at a woodland site, although in most cases this will have to be approved by the authority responsible for the site. Burials can be expensive, and although for children some of these costs may be waived it is always best to check with the funeral director and other organisations involved.

If you choose to have a bespoke ceremony you may want to look into having a direct burial or cremation, where the body is collected and buried or cremated without a ceremony. If they are cremated, you can collect the ashes later. This can give you more time to think about how you would like to celebrate their life in a way that is right for you and to plan a ceremony to scatter their child’s ashes in a meaningful place. Many families choose to have a natural burial (sometimes called a woodland or green burial) which means that natural materials are used. Information about green burial sites can be obtained from the Natural Death Centre.

Key resources

Children’s Funeral Fund in England
www.gov.uk/government/news/childrens-funeral-fund-for-england

National Association of Funeral Directors www.nafd.org.uk

Ministry of Justice: Cremations and Burials www.justice.gov.uk/coroners-burial-cremation/cremation

The Natural Death Centre
www.naturaldeath.org.uk

How do I go about planning my child's funeral service?

Planning for your child's funeral can be something that you can get immersed in, to ensure that the service captures the essence of your child and your memories of them. There are many diverse ways in which you might choose to remember and celebrate your child, with carefully chosen words, songs (or hymns) and readings, flowers and candles.

It is helpful, if possible, to have talked to your child about how they would like to be remembered and to include them in the planning for the service – it can be a source of comfort to them to be involved. Siblings can also find it helps them to feel involved if they can participate in funeral planning and say goodbye in a way that's meaningful to them. You might find it helpful to talk to a religious leader or celebrant to help you to plan the service that you would like.

Some families find solace in asking for donations in lieu of flowers at the service or in setting up tribute funds to support a charity.

"Many of my daughters' friends and her school have done fundraising events over the years since she died for her tribute fund. I think it's a good way to honour her memory and for the young people (and not so young) to channel their grief."



Section 4 Bereavement support for you and your family

Introduction

No one can anticipate quite how they will feel or react after the death of their child and you will find your own way of coping with the sadness of bereavement. Remember, it is natural and healthy to grieve, but if you feel that you or anyone in your family needs some expert support there are many options available.

What bereavement support is available?

Services that have supported your family are best placed to discuss what type of support is available to help you through the initial stages of your bereavement. Whether it's counselling, therapies or just time to remember your child as a family, do allow yourselves to take time out of everyday life and share how you are feeling. Emotional support after your child has died can take many forms. Sometimes the best support can be someone's practical help or a friend just being there to listen. Some parents find that they need expert support, provided by a range of professionals, charities and parent support groups. There are also national organisations which provide ongoing bereavement support. Many children's hospices provide separate bereavement support groups for fathers and grandparents.

Can I get support for my other children?

Children grieve in different ways and can shift quickly through a range of emotions, at one moment being very quiet and withdrawn and at another distraught and angry. It can help to find them some support, such as a playworker or therapist who they can spend one-to-one time with. Older children may want to speak in depth to someone outside of the immediate family. There are a range of organisations that can provide this kind of support for bereaved siblings.

How do I tell people that my child has died?

There will be lots of people to inform that your child has died – extended family, friends, colleagues, your child's school, benefits agencies – to name a few. You might want to think about asking a close friend or member of the family to take on the role of sharing the information so that you are not bombarded with well-meaning questions. You can ask for a member of your care team to help with sharing the news with your child's school and helping them to support pupils.



Some useful bereavement support organisations

- Bliss gives support and care to families of premature babies in the UK: www.bliss.org.uk
- The Childhood Bereavement Network (CBN) is the hub for those working with bereaved children, young people and their families across the UK: www.childhoodbereavementnetwork.org.uk
- Child Bereavement UK supports bereaved children: www.childbereavementuk.org
- The Child Death Helpline is a helpline for anyone affected by the death of a child of any age: www.childdeathhelpline.org.uk
- The Compassionate Friends support bereaved parents and their families: www.tcf.org.uk
- CRUSE is a national charity offering free, confidential help to bereaved people. It produces booklets on coping with grief that you can buy online: www.crusebereavementcare.org.uk
- Winston's Wish is a childhood bereavement charity providing services to bereaved children, young people and their families in the UK: www.winstonswish.org.uk

Section 5 Glossary of Terms

Certificate for Cremation or Burial:

The certificate issued by the registrar once the death has been registered, to allow the body to be cremated or buried.

Child Death Overview Panel

(CDOP): Responsible for reviewing information on all child deaths and are accountable to Local Safeguarding Children's Boards (LSCBs).

Coroner: A coroner is responsible for investigating and determining the cause of death, particularly unexpected or suspicious deaths.

Death certificate: The actual death certificate is the entry in the death register; what the registrar issues is certified copies of this entry, signed by the registrar (commonly called the death certificate).

Designated Paediatrician: The doctor assigned to respond to an unexpected death.

Local Safeguarding Children's Boards (LSCBs): Developed following Every Child Matters, each board is responsible for improving local safeguarding and ensuring that there is a strategic quality assurance framework to safeguard children.

Natural burial: This is where the burial involves no materials that will prevent the body from decomposing naturally in the ground. Sometimes called a green or woodland burial.

Notification: Official reporting of death to regulatory organisations.

MCCD: Medical Certificate of Cause of Death, completed by a Medical Practitioner.

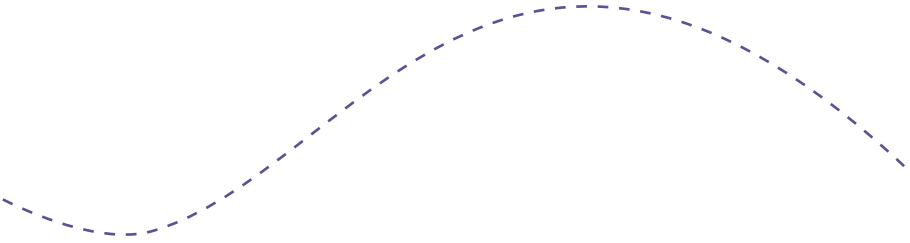
Procurator Fiscal: Responsible for investigating and determining the cause of death, in Scotland (equivalent to the coroner).

Rapid response team CDOP: A group of key professionals who come together to respond to the unexpected death of a child.

Registration of death: The official entry of death on the death register.

Verification of death: The confirmation of death.

Notes



Together for Short Lives

New Bond House, Bond Street, Bristol, BS2 9AG

T: 0117 989 7820

E: info@togetherforshortlives.org.uk

Facebook: [@togetherforshortlives](https://www.facebook.com/togetherforshortlives)

Twitter: [@Tog4ShortLives](https://twitter.com/Tog4ShortLives)

Instagram: [@togetherforshortlives](https://www.instagram.com/togetherforshortlives)

LinkedIn: [Together for Short Lives](https://www.linkedin.com/company/together-for-short-lives)

www.togetherforshortlives.org.uk