



# When your child won't get better

Your child's care, emotions, relationships,  
and practicalities at the end of their life:  
a guide for parents and carers

This booklet has been written using the real experiences of bereaved parents. Their quotes contain extra information which we hope you will find useful and comforting.

CLIC Sargent would like to thank the parents who told us their stories and played a huge part in making this possible.

Other booklets that may be of help include:

- **Living your life with a terminal diagnosis:**  
A guide for young people
- **Practical tasks after your child dies:**  
What you might need to sort out and how to do it
- **In our own words:**  
Parents talk about life after their child has died of cancer

You can order these booklets for free and find more information dealing with all aspects of end of life and grief, including videos from parents and carers talking about their own experiences, at [clicsargent.org.uk](http://clicsargent.org.uk)

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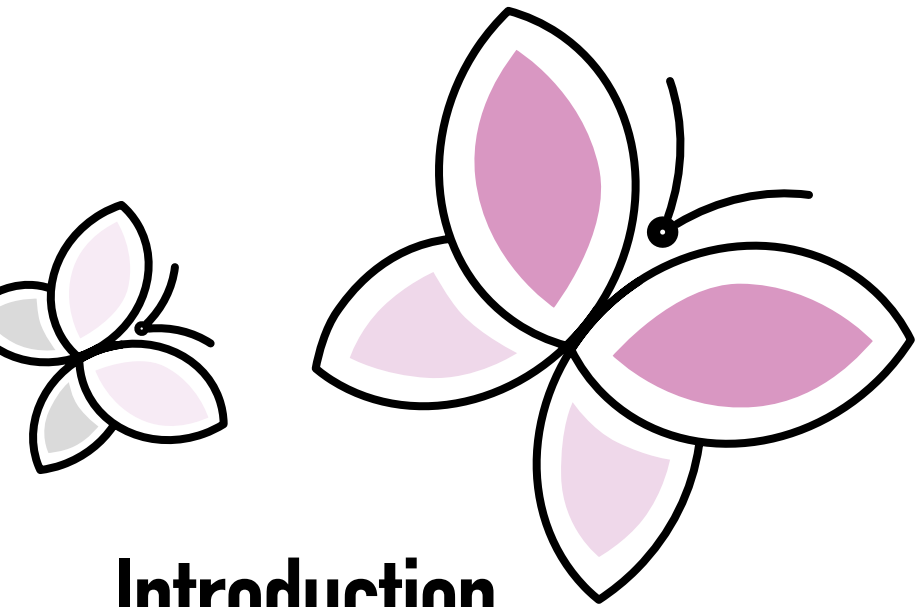
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# Introduction

There may come a time when you are told that your child isn't going to get better.

There is no right or wrong way to react to such devastating news. You might feel that your world is falling apart, you might feel numb, you might not believe what you are hearing, or maybe you knew that this moment was coming. Everyone will experience grief for the life they thought their child would have.

For some, the process is less straightforward. You may not have been told what the outcome is in black and white terms.

Whatever your situation, you need to know that you won't be alone. If you need support, or if you want to talk, ask your CLIC Sargent Social Worker, speak to someone in the team caring for your child or contact one of the specialist organisations listed in the back of this booklet.

# Your child's care

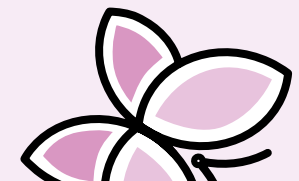
It's completely normal to have lots of questions and anxieties about your child's care.

The team caring for you and your child are there to support you. They will help you to understand more about the choices ahead of you. Although it can be painful, having these conversations as soon as you're able will help you to make decisions that are right for your child, you and your family.

Planning ahead could help you to feel more in control. Knowing that your wishes as a family have been heard and respected can give you peace of mind. It will also allow you to focus on spending precious time with your child in the last few days, rather than your attention being drawn away by having to make decisions when you might be more distressed and confused.

Remember that you'll have a supportive team of people there to help you and your child whether you're in hospital, in a hospice or at home. They are there to help you cope both practically and emotionally, so make sure you turn to them for any support you need.

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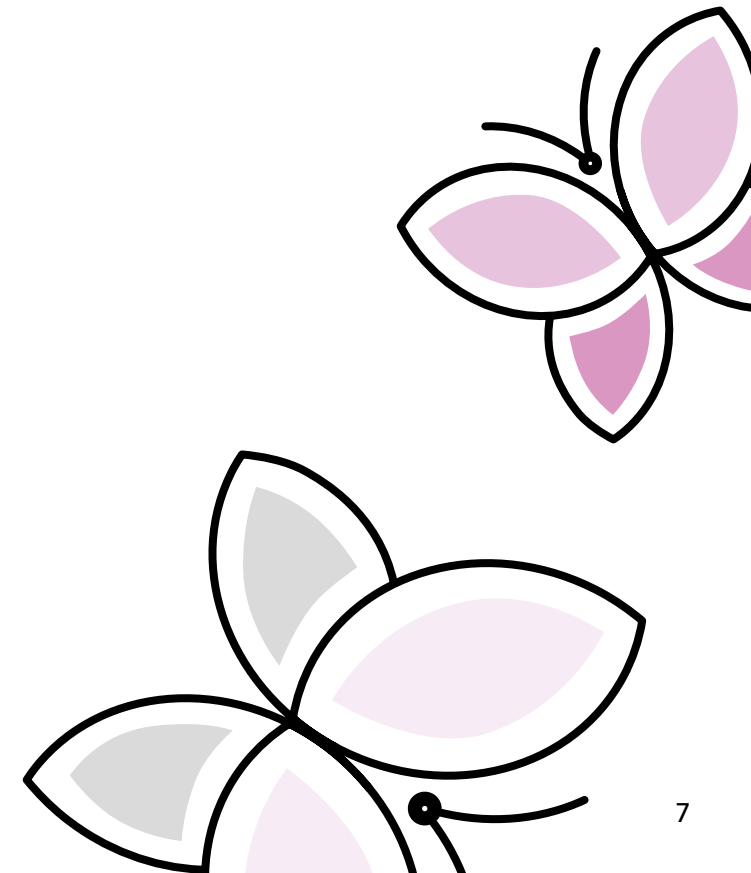
# Palliative care – what it really means

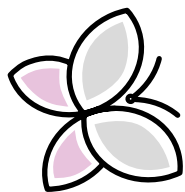
It's common for people to think that palliative care means stopping treatment and is only for end of life care. In actual fact, palliative care is the total approach to care that your child will receive to give them the best quality of life. It's often started when a cure is no longer possible but not always.

Here are five important things to know:

1. It does not make your child die sooner – part of palliative care can be deciding to stop certain treatments but it can help to manage your child's symptoms for weeks, months or even years until this point.
2. Palliative care is an approach, rather than a type of treatment. It will involve a combination of care that looks after all the aspects of your child's wellbeing including physical, emotional, social and spiritual needs.

3. It can be given at home or in a hospice, as well as hospital. There are trained palliative care specialists but this care is also given by people you see day-to-day like your GP and nurses.
4. It is designed to help you and your close family, as well as your child. Some facilities that provide palliative care will also offer complementary therapies, play therapies, counselling, spiritual support and practical advice for family and friends too.
5. It does not mean that you or your medical team have 'given up' on your child and there is no hope. This kind of care will be given with compassion to ensure that your child can live their life as fully as possible, when there are no other curative options left.





# Where your child can receive palliative care

Many people assume that their child will be cared for in hospital but this doesn't have to be the case. Home or hospices, or a combination, can provide comforting, peaceful environments where you should have all the support you need to ensure your child is well cared for and comfortable. It's up to you and your child to decide what's best for you as a family.

Although you may already have strong preferences, some people worry about making the 'right choice'. This section provides information about home, hospice and hospitals to give you a clearer picture about what these environments could offer. Try to discuss your views together as a family but be mindful that these choices might change as your child's health progresses.

You can ask your specialist nurse or your CLIC Sargent Social Worker for advice about your options. They may be able to arrange a visit to a local hospice to help you decide if this would be a good choice for you.

## At home

Home can be a comforting place for everyone. Here, your child will be in familiar surroundings with relatives, pets, possessions and toys close by. If you have friends and family nearby, their support can help ease the pressure if you or your other children need a break.

You might feel uneasy about delivering palliative care but professionals will be in regular contact, visiting often, and can provide support when it's needed. Some hospices also provide a home service, although this is not yet available throughout the UK. Check with your local hospice what services are available to you.

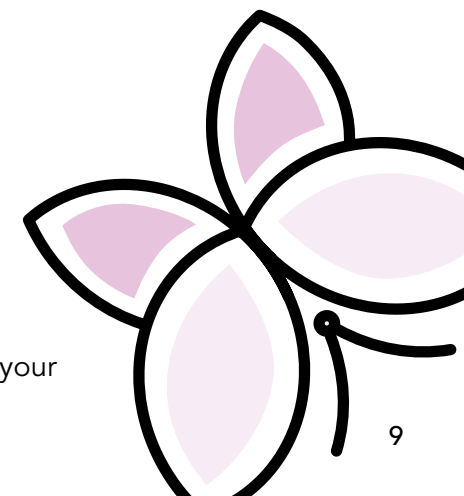
Managing symptoms at home is a free booklet by CCLG and has been written to give you information about common symptoms, their causes, treatments and suggestions for simple things that you can do at home to help your child. Or you can ask your child's doctor which symptoms to expect and how they can be managed.

*"We had a Macmillan nurse who led a team of nurses and health care assistants that visited daily whilst Hannah was at home to assist with her care and medication."*

**Simon, dad of Hannah**

## In a hospice

Hospices provide palliative and end of life care for children and young people. They work in close partnership with other care professionals and provide holistic care to your family – that is, they look after your



child's emotional, social and spiritual needs too, as well as those of siblings and parents or carers.

Many provide a range of services including 24-hour care, emergency care, short breaks, practical advice, specialist equipment, complementary therapies like massage, and bereavement support. Staff will be on hand to guide you every step of the way and will be led by your needs, giving you space or support as you need.

Hospices are very positive places that aim to fill children's lives with play and fun. You can all spend time together without having to worry about home chores like cleaning or washing, as it's all taken care of.

They can sometimes support you in your own home so it's worth asking, if this is something you'd prefer.

Hospices can be a great source of help at any point while your child is having palliative care. It's often thought that they should be accessed towards the end of life but connecting with one as early as possible could open up support you didn't know was available. This can include counselling and bereavement support for the family.

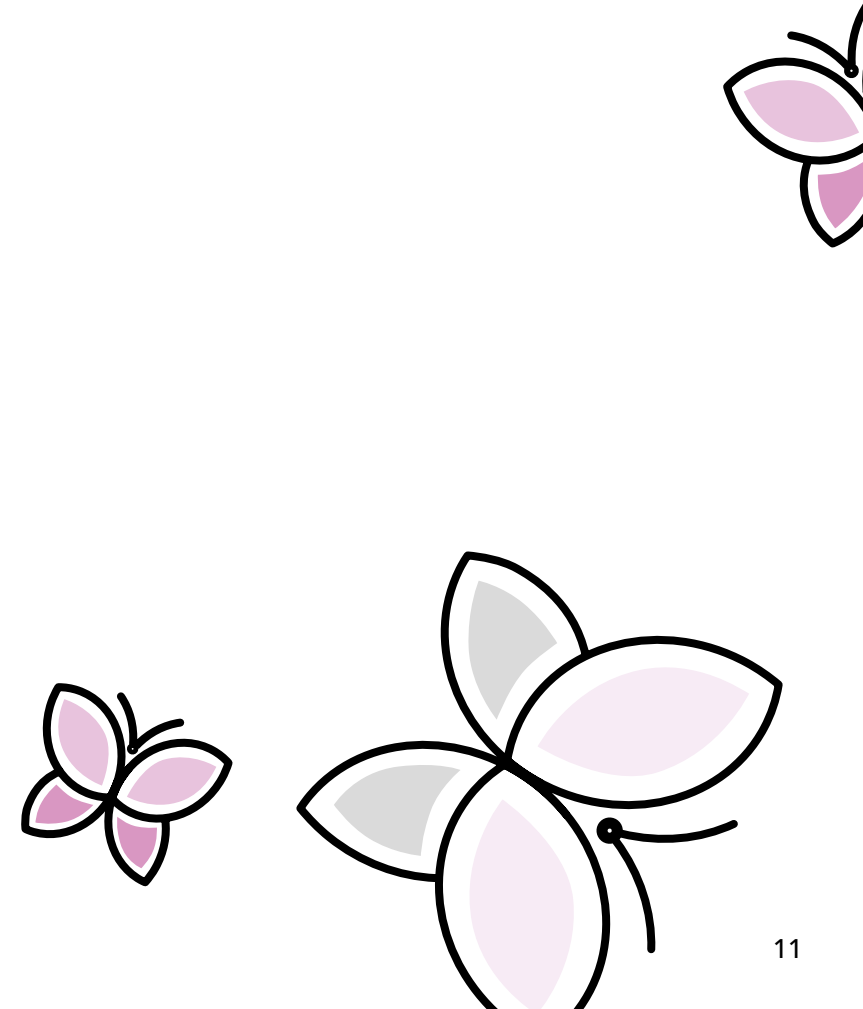
## In hospital

Your child may need to stay in hospital, or be taken back in to help manage their symptoms. Hospitals are well kitted out for attending to your child's medical needs but they may not be as well equipped to provide the emotional and spiritual care that you need as a family.

It's also more difficult to adapt a hospital environment to you and your child's needs: noise, smells, food, music, personal belongings, having pets there, and space to stay together as a

family, might be out of your control. Siblings might also need somewhere to 'escape' to if they become overwhelmed, which can be difficult in a hospital environment.

That being said, many parents will have very positive experiences in hospital – it all depends on where you are and the facilities available to you. You can be sure that your child will receive all the medical care they need and will be made comfortable each step of the way, as far as possible.





# Advance Care Planning and why it's important for you and your child

Planning for their child's death can help parents feel more in control and reassured about what's going to happen. The more plans you can put in place with your team in advance the better the chances of fulfilling your wishes, or the wishes of your child.

Health care professionals call this Advance Care Planning (ACP). They will do the planning with you to make sure your child's wishes are recorded and shared with all relevant professionals. This means everyone involved in your child's care will understand what they need to do to help you achieve that outcome. If you want your child to be at home at the end of their life for example, the plan can minimise the risk of emergency admission to hospital.

Whatever you or your child decides is not set in stone – the plan can always be changed. Your child's ACP covers:

- Where your child will die
- Treatments you do or do not want for your child
- Organ donation
- Wishes
- Arrangements for after death including the funeral

## Sacha's story: How planning can be a consolation in grief

"Days before he died, the last lucid words my 16-year-old son David, or DD as we like to call him, said were: 'I love it here.' He was looking out his bedroom window into the treetops where, at night, owls – one of his passions – would come to call.

"Three years on, I can honestly say that giving my child a 'good' death - without pain, calm and comfortable in his own bed, in the arms of his family with his beloved cat sitting on the bed, will be my greatest life achievement. And it gives me immense comfort in my grief.

"I remember the silence that hung over parents in the children's cancer ward when a family 'went home.' We all knew that meant the child was going to die but no one could say it. This taboo about death has to be shattered so that we can improve how we care for our loved ones at the end of their lives. After all, you wouldn't dream of giving birth without talking to another mum, reading books or going to a class, would you?

"When we 'went home' after DD's final scan in May 2012, which showed his cancer was everywhere and he had weeks to live, we were not doing nothing or stopping treatment – there was a detailed advanced care plan in place. It centred on the relief of

his symptoms to give him quality of life. It just was not curative treatment as this was no longer possible.

"I know that there is no medical reason why, with planning and the right support, any death cannot be managed at home like my son's, or in a hospice (I asked a very experienced Paediatrician this question.) We were managing seizures, dementia, pain and sickness from spinal and brain tumours for the last three months at home, and the number one demand from my son was that he should not have to go to hospital ever again. We succeeded, and this is where I get very upset, because we were lucky: we lived in the right area, where the services and networks existed to be able to give my son and our family that precious, precious choice.

"I consider having managed a good death for my child, fulfilling his last ever wishes as the greatest achievement of my life and my biggest consolation in the howling chasm of grief. I meet families who have not been given that choice and they tell me they will never recover and, knowing what it means to me, I know they're right."

After DD's death, Sacha wrote a book called *Follow the Child: Planning and having the best end-of-life care for your child*. It offers a parent's perspective about what to expect during this time. The book gives practical advice, including drawing up an Advance Care Plan, how to move care into the home and how such things worked in her own family's story. It also includes examples from other families who made different choices around their child's death and advice from healthcare professionals.

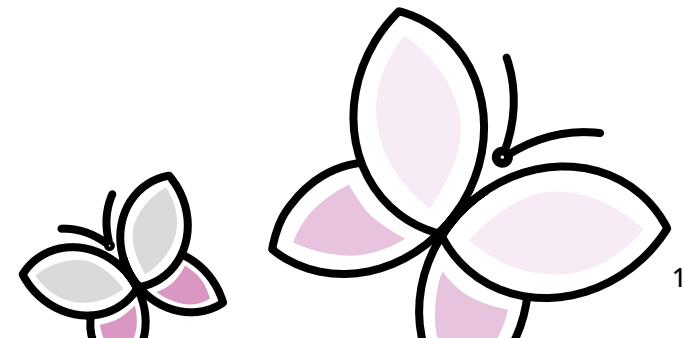
## If planning isn't possible

Thinking about your child's death, asking questions, having conversations and planning does not mean you are 'giving up on your child' or that you have given up hope. Rather, you are helping them by preparing yourself and the people involved in their care.

Of course, every situation is different and for many parents, it isn't possible to plan because events might happen quickly or unexpectedly. Some parents aren't given the opportunity to discuss options because of poor communication.

It can be difficult when you are not given clear choices, or do not have the time or opportunity to think about your options. If for whatever reason your circumstances end up determining what happens, you might feel very out of control. Whatever happens though, you'll have the expertise and support from people around you to guide you through.

So – much like with birth – plan for what you can, with the knowledge that it might not happen exactly as you'd prepared for. The more discussions you have and plans you put in place, the likelier it is that you'll have a controlled, coordinated and supportive experience.





# Relationships and family life



Talking to your child about dying might feel impossible. You might also be worried about having conversations with your child's brothers or sisters, or your wider circle of family and friends. You might not feel ready but it's important to be prepared. Many children and young people pick up on what's happening around them, including siblings. Although it's painful, it helps to be as honest and open with each other as you can.

Good communication – whether it's with family, friends, professionals, colleagues or school – can make all the difference in getting the support you need. Just make sure you do what feels right as a family and focus on creating happy times together.

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# Talking to your child about dying



How, when and whether you talk with your child about what's going to happen will be steered by many things, like your child's age, personality, level of independence and your own views about what is right for your child.

## Should I tell them?

It's normal to want to protect your child. You might believe the best way to do this is by not telling them their prognosis, especially if they are very young.

However, many children will suspect what is going on because of how they feel. They could also become aware by observing what's happening around them, such as people visiting more and the general atmosphere. So it's best to prepare for having a conversation with them, whether you initiate it or they ask you outright.

It can be very hard if you and your partner have differing views on this. Coming to an agreement might not be easy – there is no 'right' answer and it will take honest conversations and compromise but ultimately, your decision will be in the best interest of your child.



“My husband didn’t want my 13-year-old son to know he was going to die and wouldn’t talk about it, but I felt it was important to be honest and give him the opportunity to talk. Ultimately, we agreed that we wouldn’t bring it up unless he asked directly, which as it happens he did.”

**Sarah, mum of Tom and Hazel**

Sometimes, you may not have been told outright that your child is going to die. It’s more a slow realisation or growing understanding in the back of your mind. Let them know that it’s ok to talk about anything with you. They don’t need to stay strong for your benefit. Keep looking out for signs that they’re ready to talk.

## How much will they understand?

Your child’s developmental level will play a major part in their understanding of death. Preschool-aged children are too young to understand the concept of death—particularly its permanence. School-aged children are just beginning to understand death as a final separation. Meanwhile, teenagers typically have an adult understanding of death, but it directly challenges their feelings of immortality and their growing need for independence.

## How do I know if they are ready to talk?

Look out for opportunities to talk about what your child is thinking and feeling. This may include the illness of a character in a movie or in a television show. You might also want to start by talking about what has happened so far and asking your child if there is anything they are thinking about.

This goes for teenagers too. Some may be able to communicate clearly about what they do or don’t want to talk about but they may also hold fears and thoughts that they might find difficult to share. They may also be reluctant to talk because they’re feeling

guilty or are trying to protect you. Simply letting them know you’re there to talk about anything can give them the permission they need to open up.

With younger children, listen for signs that your child is ready to talk or wants to explore the concept of dying with you, even though that’s obviously extremely painful for you. Your child might do this indirectly, for example, by asking what you think happened to a pet after they died. This could be their way of broaching the subject with you.

You may also face direct questions from your child that can take you by surprise and feel very painful. This is why it’s important to at least be prepared so that it doesn’t catch you out, and you can use this opportunity to talk openly. This way, they’ll know they can come to you with any more questions or worries and they can trust you to be honest with them.

## How do I talk to my child about dying?

This can be an incredibly painful discussion to have but it might be important for your child that you do. Here is some advice for having this talk.

### Where and how

Often it is easier to have this type of conversation while your child is doing an activity to remove some of the intensity and pressure. If possible, try to make sure your environment is calm and comfortable. Conversations can’t always be planned for though. Your child may surprise you with a direct question whilst watching TV or having a bath. If this happens then go with it and be led by your child.

If they change the subject, become fidgety or move on to another activity then that probably means that they want to finish talking for now. That’s ok – sometimes it’s better to have a series of shorter chats than one long one.

## Be honest

You might feel anxious about saying the wrong thing but avoiding the subject, especially if your child has raised it, can create more confusion and fear. Explaining to your child that the treatment isn't working anymore and that they aren't going to get better will be incredibly difficult for you. But being honest will help your child feel less anxious if they have an idea of what to expect. Don't be afraid to cry. Your tears can give them permission to cry too.

It's important to use clear language. Using terms like 'passing away', 'going to sleep' or 'going to a better place' can confuse and mislead children. Some children will also want a biological explanation. It can feel severe to explain to your child that dying means a body will stop working and people will no longer breathe or eat or feel pain. Many parents understandably won't be able to talk about it in these terms but there are resources on page 67 to help.

The conversation doesn't have to be traumatic if you can talk in a way that makes your child feel safe and comforted. Reassure them that you'll be with them every step of the way.

Support and advice can be given by your CLIC Sargent Social Worker, community nurse, CNS or local children's hospice. These services can help you prepare for this conversation and guide you with the language to use. They can also offer to be with you if there is a time planned to talk with your child and in some circumstances will have the conversation for you if you feel unable to do so.

## Ask questions

Give your child the opportunity to ask questions and encourage them to explore issues with you. This will let them know that they can talk to you when they need to. Remember that it's ok to say that you don't have all the answers.

It can sometimes help to ask them questions as well. Try to make sure they're open-ended rather than 'yes or no' so your child can explain themselves in their own way, without feeling like there's a right or wrong answer. It is a good idea to ask them what they think will happen to gauge what their understanding is before you start to explain in your own terms.

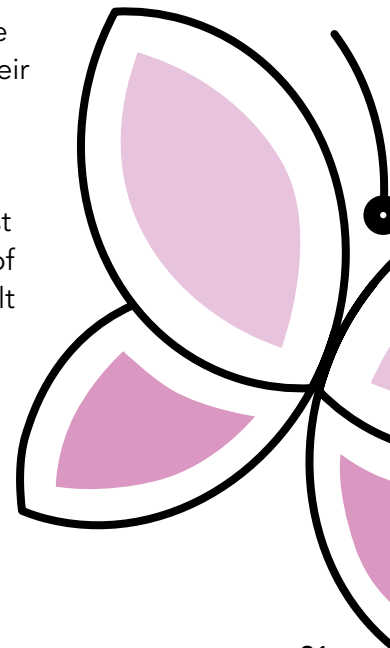
## Address pain

We all hope that dying will be as peaceful as possible, and your palliative care team will work hard to manage all eventualities. Whatever happens, your child will be with people that love them and can be kept comfortable by whoever is looking after them.

## Use comforting thoughts

Reassure your child that he or she will not be alone. It is important for children to know their parents will be with them when they die and that parental love and support will continue. Be aware that it doesn't always happen as you'd expect or wish – some children die just at the moment when their parents pop out of the room. Many parents harbour terrible guilt for this, so tell your child that you'll be with them, whilst knowing that you can forgive yourself if you aren't.

Some parents like to say that a loved one will be waiting for them.



“Although we weren’t really religious, when my son was very ill we were visited by a minister who described dying as going into the sea for the first time when you’re little. He said that to start with the waves seem big and scary but you’re holding on to your mum’s hand and after a while it doesn’t seem so scary anymore. He said when you let go of your mum’s hand Jesus would come and take your hand and walk with you, so you wouldn’t be alone. This thought really comforted my son. When my daughter was dying I told her that she had fought long and hard enough, and it was time to rest now. I said that when she let go of my hand that her brother (who had died before her), would be waiting to take it instead, and that it was time to go and be with him until we could all be together again.”

### **Sarah, mum of Tom and Hazel**

If your child has strong feelings about certain things they want, like where they want to die for example, then you can also let them know that you’ll do everything in your power to make sure their wishes will be fulfilled.

### **Acknowledge guilt**

If your child is a teenager, they may be harbouring feelings of guilt about being a burden or feeling that they are causing you and others around them sadness. It’s not uncommon for children to experience this to some degree as well, worrying about leaving their parents.

Sometimes, it can help to give your child ‘permission’ to talk about dying, simply by saying – “I’m ok to talk about this. I’m here for you”.

## **What about religion and spirituality?**

Your child’s understanding of death may be influenced by your family’s religious beliefs, and possibly things they may have seen on TV or read in books. It’s common for children to know about heaven or angels, and you could use this if you’re comfortable with that idea. Believing that they will go somewhere beautiful or re-joining other family members who have died can help children to feel safe.

Be cautious though if this isn’t something your child is familiar with, as introducing new concepts may cause more confusion.

If you don’t hold a particular belief, you’re still likely to want to include some comforting thoughts and concepts, but it can be tricky to do this without feeling like you’re being dishonest. You could try talking about death as a natural cycle and that everything will eventually go back into the earth, which will help plants to grow and feed new life. You can tell your child they will always be all around you, up in the stars and in your heart. You could find a metaphor that works for them, like a boat sailing into the sunset, a rocket flying into space or setting off on a new adventure.

If your child is a teenager, they may have formed different beliefs to you, or may not believe in anything after death. It’s important to respect their views and listen to how they feel. It might be something you can explore together.

If your culture or religion restricts open discussion, or you simply can’t broach the subject because it is too painful, try to remember that silence can feel scary for a child. Let your child know that they can talk to someone else about their fears, so they are not left to their own imagination and the unknown.

## How will my child react?

Give your child a bit of time for all this to sink in. They may want to return to the subject later and might even choose to ignore it. It's quite common for younger children to respond to devastating news in surprisingly 'normal' ways – like asking to go and watch TV, or changing the subject. This goes for siblings too.

Sometimes, your child might talk about the future even when they know that they are going to die. This may seem worrying but go with it – it's just their way of processing what's happening and needing to talk about it as though it wasn't.

Older children and teenagers will sometimes want to start actively playing a bigger role in what's ahead. They might start making decisions about their funeral, or find special ways to say goodbye to people.

If your child is open and willing to talk about things with you, there are a few things you might want to ask them to help you have a clearer idea of what to do further down the line. If they have already mentioned their funeral, you might want to ask if they have any particular wishes so you can fulfil these when the time comes. It's also a good idea to ask them about what they want to happen to their online accounts and to write down any log in details – if they're happy to share them with you. This can prevent a lot of heartache and frustration trying to access your child's data and manage their digital legacy in the future. You could also see if there's anything nice they'd like to do as a family – you can read more about this in Everyday life and making special time on page 37.

## Where do I go for help?

Social workers, nurses, child psychologists, hospice staff and other palliative specialists can give advice about how to talk about death with your child. If you are able to, pick one you know and are comfortable with. Your child may find it easier to talk about the feelings of a sick teddy bear or a child in a picture. Play specialists could also help younger children to communicate through play or art.

You may find it helpful to use a book to explain death. You can find helpful resources that other parents and carers have recommended at the back of this booklet on page 66.

Bereaved parents will also be able to share their valuable insight and range of experiences with you. You can find communities and groups online, or by asking your medical care team or hospice.

*“As part of our Facebook support group (My Kid Has Cancer), sometimes a parent will be in that situation of end of life care with their child and I and fellow bereaved parents have been able to provide advice, comfort, understanding and the knowledge that they aren't alone. For me that understanding is invaluable.”*

**Simon, dad of Hannah**



# Talking to siblings about their brother or sister dying

How you talk with your other children will depend on their personality, age and your relationship with them. Whatever the circumstances, there are things you can do to help – like letting them know you're here and following their lead.

## Understanding what they're going through

It's common for brothers and sisters to feel left out while your other child is going through treatment. They could be experiencing difficult and complex emotions, like jealousy, resentment or guilt. So it's vital that they feel important and loved. Sometimes, it's easier for them to talk to someone outside the close family circle, like a social worker at the treatment centre, if they've spent lots of time there, or a family friend.

"In most situations I know of, the sibling either is, or feels, side-lined no matter how much parents will try not to, and this happens throughout treatment. They will often feel guilty about sharing their own feelings, especially to their parents who they know are going through difficult times too, so they will keep it to themselves for fear of upsetting family members."

**Simon, dad of Hannah**

## How do I tell them?

Your child's siblings might already be more aware than you think. It's quite common for brothers and sisters to pick up on what's going on around them. If they go to the same school then they might have already been faced with tough questions from classmates.

Being honest with them might not be easy but preparing them can save pain in the future and will help prevent them from feeling confused, anxious or isolated. It also builds trust and gives them the opportunity to spend special time with their sibling. You could ask a professional to do this with you if you feel you might need some support.

## What will their reaction be?

Children can often appear surprisingly indifferent after being told devastating news. They might seem like they've heard nothing and go back to whatever activity they were doing, or change the subject. This might feel both painful and infuriating but it's a common reaction to shock. They might also become angry, insensitive, quiet and insecure or shift quickly from one of these behaviours to another.

Remember that this is an ongoing process. Younger children will need small chunks of information over a period of time.

Keep encouraging them to express themselves by asking what they're thinking about or how they're feeling.

Teenagers and young adults may want to talk in more depth and may want to play a more active part in helping out. They could also become angry or seem disengaged. Give them some time to sort through their feelings.

You can come back to it later – it might not be right for them to talk right now, and that's ok. Just let them know that you're here and go at their pace.

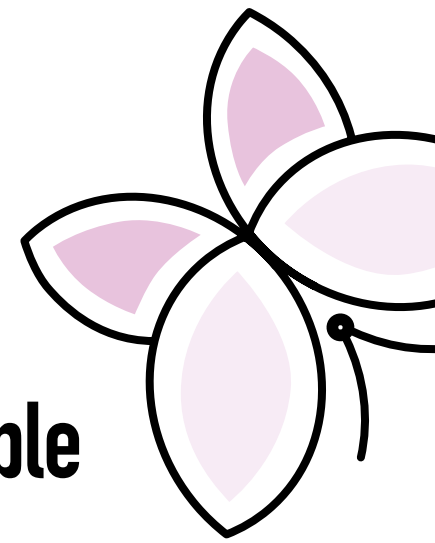
### **Should I talk to their school?**

Teachers can be an important source of support. Involve them as early as possible so they can be kept in the loop. This will help them understand what siblings are going through and make sure they are getting the best support in school.

Parents report having mixed experiences with support from schools – some might be fantastic, while others might not step up in the way you'd expect. If you're having any problems, seek support from your social worker or talk to a member of the team caring for your child.

If your child and their siblings go to the same school, you can read more about talking to the school on page 32.

Find books and resources at back of booklet on page 66 for talking to brothers and sisters



## **Telling other people that your child's treatment has failed**

It's natural for family and friends to be worried and want to know about your child. Before telling people, prepare yourself. Think of what you want people to know, and how you may react to their questions and emotions. The most important thing is that you do what's right for you as a family.

### **How do I tell my family and friends?**

Breaking the news isn't easy and it could make everything feel more real for you. Before talking to anyone, step back and think about how much detail you want to share. This might depend on how much your child already knows, or can cope with knowing. Be clear and firm with people, and ask them to respect your wishes around how much is shared in front of your child.



“I’ve known situations with other parents where family or friends, often not particularly involved in the child’s welfare throughout treatment, will share information almost in an attempt to be the first to break the news or to get sympathy from their circle of family and friends because they have shared this ‘sad’ news. So as well as thinking about what to share also think about who to share it with.”

### Simon, dad of Hannah

If your child is aware of what’s happening then you might want to talk with them to get their opinions about the best way to go about things – how much they want to share, who to tell first, how to break the news and whether they want to play an active part in having these conversations.

It will be easier with people who you’ve shared a lot with already. Honesty and openness is usually the best way forward when having difficult conversations, so don’t be worried about showing your own emotions or ‘getting it right’. Just explain the situation in the best way you can.

If it’s all getting too much and you need to take a time out, just say so. You might choose to talk to several people at once to save repeating this process or ask your CLIC Sargent Social Worker or another professional to be present while you do this, to help support you or answer any questions people may have. You could also nominate someone else to share the news with friends, co-workers and parents at school.

If you’ve been sharing your child’s progress online, then it might feel natural to write a post for your blog or social media. Just be mindful of comments and messages after you post.

## How do I tell my work?

Try to be open with your manager about your situation - most will try to support you during this difficult time. Keeping them informed may well help them to work with you to put supportive arrangements in place. If it helps, your CLIC Sargent Social Worker can contact your workplace on your behalf to discuss your options with your manager or HR department.

When it comes to taking time off, here are some possible options:

- Talk to your GP about a Statement of Fitness to Work (or ‘fit note’). They may exempt you from work, advise on reduced hours or recommend flexible working
- Talk directly to your employer about reduced hours or flexible working – many employers will be sympathetic and may be able to accommodate a change of your work arrangements
- Talk to your employer about special leave or compassionate leave. However, you need to be aware that this leave may be unpaid
- Talk to your employer about unpaid leave if you can afford to and wish to have time away from work. It is important to take advice about the implications of unpaid leave for your national insurance, pension and continuity of service.

If you are worried about finances, are self-employed or already receiving benefits, talk to our welfare advice team for free support and advice. Contact **0800 915 4439** or [welfareadvice@clicsargent.org.uk](mailto:welfareadvice@clicsargent.org.uk)



## How do I tell my child's school?

If your child still attends school or sees their classmates, sharing the news could have a big impact on them – so think about it first and if appropriate, get your child's opinion too.

Talk through your wishes with a teacher and make sure they are crystal clear on what your expectations are. You might be happy to share what's happening with your child's classmates. Or you might want it kept discreet for the time being, especially if your child isn't fully aware and still goes to school, or their sibling does.

However, bear in mind that the school or teachers may also hold their own opinions on what, where and with whom the information should be shared – it may be that you won't have full control over how the school manages this.

If your child continues attending school and wants their friends to know, they may need extra support in place from staff to help with questions or comments. It's also a good idea to talk about their physical and emotional needs, and how the school might support them with this. Check if your child's school has a palliative child or bereavement plan and if not, encourage them to make one. The charity Winston's Wish has expert advice on this that schools can access.

Your CLIC Sargent Social Worker can help you to think through your options and communicate with the school. You might even want to share this booklet with someone at the school so they understand what you and your family are going through.

## What about my child's friends or partner?

If your child is aged 16 or over then they – and you – might want to look at the information on [clicsargent.org.uk](https://clicsargent.org.uk) for teenagers

and young adults. It's designed to help young people talk to their family, partner and friends about what's happening, how they feel and what they might need.

## What reactions will I get?

When telling people face-to-face, experiencing their reactions can be distressing. At first, people may respond with a range of emotions, from anguish and anger, to shock and numbness, or even awkwardness.

Some people's comments might be a great support, or you may find them unhelpful, or even insensitive. It's not unusual for people to find it hard to know what to say, or what words to use, even when they mean well. It's likely they'll need time to deal with their feelings so try not to take it personally if people don't respond in the way you might expect.

In the longer term, people may find it difficult to understand how your life has changed. They will try to be supportive but they may not know how to approach you or how to talk to you about what you are going through.

You may find that people you had been close to drift away as they are not able to cope with painful emotions. Other people may surprise you and be supportive and helpful in ways that you would not have imagined. Make sure you take full advantage of any offers of help, especially for practical tasks such as shopping, cooking or helping to support a normal routine for your other children.

*"Sometimes, the most supportive people are those you don't expect, and some of the people you would expect to be great are rubbish."*

**Sarah, mum of Tom and Hazel**

## How do I deal with people contacting me all the time?

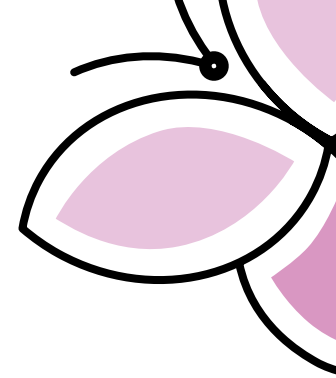
One mum said that people contacting her became a bit relentless and she was forever on the phone and missing time with her son. She asked people to ring or message her parents for updates instead so she could focus on enjoying precious time with her children.

If you are being overwhelmed with responses then it can be really upsetting to have to get back to everyone and answer questions over and over again. Usually these people are well meaning and don't mean to cause additional stress. But it's important to put your needs first and it's ok to not want to talk all the time.

Share the responsibility with someone who is willing. Give someone in your circle of friends and family the role of being someone a 'go to' person who gives out information and to whom everyone messages with their questions. Choose someone you trust and give them clear information that you are happy to share.

*"We had a Facebook page for Hannah which we used throughout her treatment to keep people updated on what was happening. It was invaluable to us as it meant we only had to update once, rather than repeat for each person but also people could keep updated without feeling guilty about contacting us."*

**Simon, dad of Hannah**



## Supporting yourself

Being told your child isn't going to get better will be one of the hardest things you'll ever hear. There is no 'normal' way to react and any feelings or numbness you're experiencing right now is natural under these unthinkable circumstances.

For parents and carers of a child with cancer, life changes at diagnosis. For a long time now, you may have been at your child's side through treatment, or holding the fort at home, while dealing with the turmoil and complex emotions that this 'new normal' brings.

Grief comes in many forms, and 'anticipatory grief' is something you may have already experienced. It's linked to loss – a loss of your child's independence, a loss of stability, a loss of your identity, and any other losses that have come from your child's illness as it has progressed.

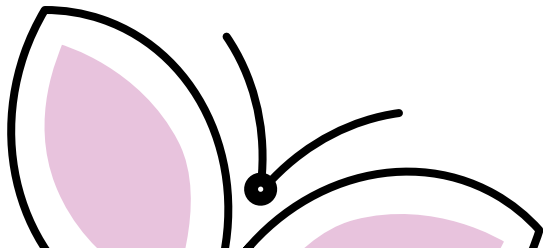
You might have felt sadness, anxiety, anger, isolation, dread, forgetfulness or depression. These feelings can be difficult to deal with, especially when they are combined with the other stresses that come with caring for your child. When you are told that your child's treatment is no longer to cure them, these feelings might become much more intense. You might not be able to stop yourself from imagining the future, or find yourself waiting for the inevitable to happen.

Remember to not beat yourself up over how you're feeling. If you are grieving, or planning for the end of your child's life, it doesn't mean that you are giving up. What you are feeling is completely natural. Living with uncertainty, shock and sorrow can take a huge emotional toll though, so it's important that you get support for yourself too.

Connecting with others going through similar experiences is something that other parents often find helpful. Your social worker or someone in the team caring for your child might be able to point you in the direction of local groups or online forums where you can talk to others who will understand what you're going through. You could also look into getting counselling for some extra professional support, tailored to you.

Take advantage of the people around you who want to help – reach out to friends and family who can give you a shoulder to cry on, or a listening ear so you can vent. They could take on some practical tasks for you, like childcare or household chores. This could help free up some time that you could spend taking care of yourself.

Taking time out to care for yourself doesn't necessarily mean booking yourself into a spa – it can simply be getting some time alone, whether that's going for a walk, having a nice long bath or watching something on TV. It could be meeting up with a friend or catching up with a hobby. It's easy to become consumed by what's happening, but taking a few minutes for yourself here and there can help you to have more energy and feel just a little bit more resilient so that you can focus on the special time you and your child are spending together.



## Everyday life and making special time

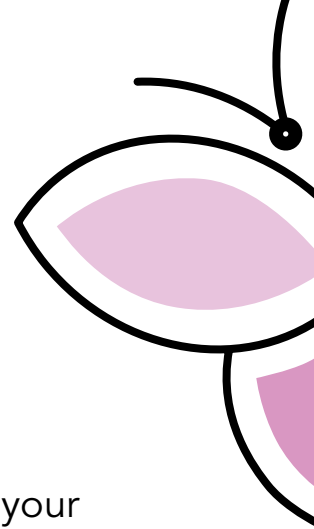
Time is so precious, especially when your child is feeling up to doing things. Choose very carefully how you use this time and be cautious about accepting too many holidays and treats. It's important to find a balance between enjoying the little things that life has to offer, and making special memories.

### Is it important to continue routines?

You're bound to want to make this time as special as possible but it is important to maintain routines where you can, as well as the good behaviour you normally expect. This goes for brothers and sisters too.

Children and young people like consistency and it will help your child and their siblings feel more secure. Obviously this won't always be possible so you'll need to make a judgement call on which routines you can keep in place.

School might seem insignificant but for your children, this sense of normality and activity can be a huge help. You could talk to the school about whether they can support your child going in for part of the day, or arrange a visit with some classmates if they are too unwell but would like to spend time with friends.



## How can I create special times?

It's a nice idea to sit down with your child and talk about the things they might want to do; or things you might want to do together as a family. These experiences can not only be great fun, but will create some lasting memories for you all to hold on to forever.

Your child might start thinking about a 'bucket list' of special things they want to see or do, like going on holiday, watching their favourite team play or meeting a celebrity. Many families treasure these experiences and, although not everything is always possible, there is help to make it happen.

*"We tried to do lots of fun things and we always laughed"*

**Sarah, mum of Tom and Hazel**

Some charities organise and fund outings, holidays, experiences and gifts for kids and teens with serious conditions – they'll speak to your child's consultant to make sure it's ok from a medical perspective. Your CLIC Sargent Social Worker might also be able to point you in the direction of local organisations or grants you could access, or look at our website for more information.

Remember though, you don't have to push the boat out to make memorable moments. Making a memory box can be comforting for your child and their siblings. You can collect special things and then talk together about what's important and why. For older children, it can reassure them how significant their life has been and gives them an opportunity to celebrate what a difference they've made.

Be guided by your child as they may be most happy with short outings to favourite places, or just doing simple things and

familiar things at home or with their friends. The medical team can support you and your child to manage physical symptoms and enable trips and treats.

*"Taking lots of photos and videos is very important, as is including their siblings in everything. One thing I wish we had done is a child or family hand cast."*

**Simon, dad of Hannah**

## How do I look after my child at home?

It can feel like a big responsibility taking care of your child at home when you don't know what to expect. Remember that there will always be medical and emotional advice available from the team caring for your child at any time that you need it and from resources on and offline at specialist charities. Planning with your team gives you the best chance for you to get things right with your family.

*"Instead of going back and forth to the hospital with the unrealistic hope that he was going to be cured and putting him through more suffering, we focused on keeping him calm and comfortable at home. My big fear was that he'd be in pain. That was my biggest terror. But there is nothing that can't be managed at home. If I can do it, anyone can."*

**Sacha, mum of 'DD'**

CCLG produce a booklet called Managing symptoms at home which gives information on specific symptoms and general care including nutrition, complementary therapies and relaxation.



# The end of your child's life

The end of your child's life will be a personal experience. You'll be going through some powerful emotions during this time but try not to be worried about what is normal or expected. Just make sure you have the knowledge and support to make decisions that are right for you and your family.

You will need to think about where you would like your child to be cared for towards the end of their life and afterwards, whether that's in hospital, a hospice, at home or a combination of all three. Wherever you are, you should have skilled and experienced professionals to hand. They will guide you and enable you to care for your child as much as you feel able.

It's normal to have lots of questions about the end of your child's life. Although not all of them will have clear answers,

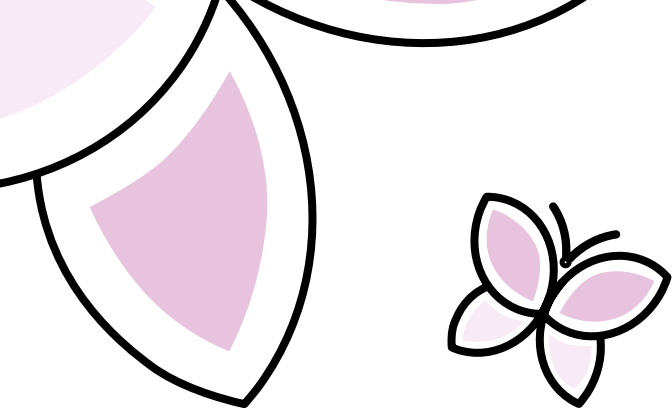
the information in this section was designed to give you an overview of the where and how, what you'll need to think about immediately afterwards and a clearer idea of what to expect.

*"Knowing a bit about how end of life care worked, what to expect and what you can do made us feel so much less frightened and gave us some control. It was such a relief to know our son's wishes would be respected."*

**Sacha, mum of 'DD'**

Please note, although we always aim to speak about death as sensitively and compassionately as possible, some of the information in this section might be difficult to read. Make sure you have support close by or you can find details of organisations that could support you on page 66.

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# What will happen when my child dies?

Death, much like birth, is different for everyone. What you can and should expect is that no matter where they are, they will get medical support to make sure they are as comfortable as possible. Everyone involved in your child's care will talk with you honestly, with respect for your fears, wishes and feelings. We try to answer some common questions from parents below.

## Can I help with palliative care?

Doctors and nurses can help you be closely involved in the care of your child, if this is what you want. They know that you are the expert when it comes to looking after your child. If you are thinking about complementary therapies to help to manage your

child's symptoms, discuss your plans with the staff looking after your child. They can advise you on the best way to introduce and use these therapies. It's always best to take advice from medical staff if you are considering introducing any medicines or therapies other than those prescribed by the specialist team.

## How will I know when my child is nearing death?

Your child's body will slowly start to slow down which means they might need to sleep a lot more and be less responsive when they are awake. They might also slip in and out of consciousness, sometimes seeing or hearing things. They might not want to eat or drink much, and have less control of their bladder and bowel movements. Breathing patterns can change and their skin might feel cooler. Sometimes, people can also become restless or confused but your calming presence and attending to their medication might help to ease this. Not everyone will experience these though, and it might happen more rapidly.

Death, just like birth, can be hugely variable though and it's always best to talk through your concerns or questions with the palliative team caring for your child.

## What do I need to do when I think my child is near death?

It can be difficult to know when your child is approaching death but if you are at home and feel you need support, you can call your nurse or whoever is coordinating your care to request a medical professional to come and be with you. Talk to your palliative care team beforehand – they will provide advice and support to help prepare and guide you.

Hospice staff will be highly skilled and experienced and able to support your child as they reach the end of their life. They will help you to create a calm and peaceful environment for your





child and will support you in whatever way you need during this time. They can usually accommodate anyone else you and your child want with you. It's important to respect the wishes of your child and their siblings when you think about this.

## Will my child be in pain?

The team looking after your child are highly skilled and experienced. They will do everything that they can to make your child peaceful and comfortable at all times but your child might then not be awake; it's a balancing act that you and the whole team will discuss and manage.

## How can I help my child?

Sometimes young people and children 'hold on' because they sense people's sadness and don't want to upset you. One of the most important things you can do for your child is give them permission to let go. This doesn't have to be through words. You can do this by creating a peaceful and calm environment – maybe lowering lights, playing soothing music and having their pet close by. If you're in hospital your presence, touch and voice can be a great comfort. Even if your child isn't fully conscious, they may still be able to hear you.

Reassure them that it's ok and that you'll be alright. You could let them know that a relative will be there waiting for them, or to use a story to take them on a journey – something called guided imagery or visualisation.

## How will I cope?

The thought of coping with the pain after your child dies can seem impossible. On the other hand, you might feel a sense of relief that they are no longer suffering – although this might make you feel guilty, it's quite common for parents to feel this way. It's also normal to feel quite numb and go into 'autopilot'

while you make arrangements for the funeral. Everyone experiences grief in different ways at different times but you can be sure that anything you feel is completely normal.

Although you might feel lost, you won't be alone. Family, friends and your community might want to help – though, you might have to help them understand what you need. You'll also have the knowledge and skills of an experienced team of professionals who will help you and guide you through the choices ahead of you.

In our own words is a free booklet about grief when your child dies. It contains experiences and stories from other bereaved parents so you can read about what others went through and how they coped. You can also find lots of information about grief and videos from other parents at [clicsargent.org.uk](https://clicsargent.org.uk).

## Is there anything I can do to take care of my child after they've died?

Whether you're in hospital, a hospice or at home, you should be supported to care for or spend time with your child – whether that's to have a cuddle, remove medical equipment, tidy their appearance, take a lock of their hair or a handprint, or to just be with them.

### At home

At hospital, staff would usually tend to your child by washing them, replacing any dressings and dressing them in clothes or nightclothes of your choice.

This can be an important and comforting ritual for parents to perform at home too. There may also be specific cultural or religious preparations you'd like to carry out. You can take as much time as you need to do these things, to have family round

and to say your goodbyes. You can even keep your child at home until the funeral if you wish. It's best to talk to a funeral director first so you can make the environment suitable.

If your child stays at home, at some point they will need to be moved. This can be arranged through your funeral directors or you may use a private ambulance service.

“Once Hannah’s death was confirmed by the nurse specialist, all the medical staff left us, taking some of the medical equipment away with them. The following day we contacted our local funeral director who took care of everything, coming to take Hannah away and making further arrangements.”

**Simon, dad of Hannah**

### **In a hospice**

After your child has died, the hospice will enable you to care for, or spend time with your child however you need to – whether that's to have a cuddle, remove medical equipment, wash them, tidy their appearance, take a lock of their hair or a handprint or anything else you'd like to do.

Most hospices will have private and peaceful spaces where you and other family members can spend time with your child at any time until the funeral. Or you can make contact with a funeral director who can look after your child at their parlour.

It might also be possible to take your child home, either before or instead of, going with a funeral director. This means you can take as much time as you need to do these things, to have family round and to say your goodbyes.

The staff will help you to make arrangements and aim to uphold your choices about where you want your child to be, getting the relevant medical certificates and any practical or emotional guidance you need during this time.

### **In hospital**

The ward staff should arrange for you to have as much time as you need with your child. Hospital facilities vary, but your child can normally stay on the ward so family members can come and say goodbye. Some hospitals will have a more private space, such as a side ward or a special room.

At some point your child will need to be moved from the ward to the hospital mortuary, unless they are a new-born. The funeral directors of your choice will make arrangements to collect your child and to take them to the funeral parlour while arrangements are made. Or you can talk to a funeral director about taking your child home to be with you until the funeral, and how to make the environment suitable.

## **Where will my child stay before the funeral?**

After your child dies, you have a number of choices:

- Your child can be taken to a funeral parlour when you are ready and remain there until the funeral. You can make arrangements to visit them here if you like.
- Your child can be taken to a funeral parlour and then return home at any point before the funeral.
- Your child can be taken to a hospice, where they have facilities where your child can stay, with you if you wish, until the funeral.
- Your child could remain at home with you until the funeral.



For some parents, being able to keep their child at home after death is an important time to prepare for the final goodbye of the funeral. It's not an easy thing to think about but it's important to know that there will be some physical changes that happen to your child's body after their death. It's best to talk to your nurse to prepare yourself. If you plan to keep your child at home for more than a couple of days, talk to a funeral director and your nurse about making the environment suitable.

"In Hannah's situation she was taken by the funeral director the day following her death in the evening on Thursday, this was quite soon after we had contacted them. We managed to arrange fairly quickly that her Celebration of Life would be the week on Monday and that the coffin we had chosen would be delivered on the Wednesday and that she would be brought home in it to spend the time at home between then and the Celebration of Life."

**Simon, dad of Hannah**

## Being separated from your child after death

The point when you have to say goodbye to your child is likely to be very emotional. If they're at home then you may prefer to remain in another part of the house or choose not to be at home. You can carry your child from your house or you may ask for help from your family or the funeral director/ambulance service.

## Can I donate their organs?

An organ donation is not usually possible if your child has died after cancer treatment. However, you may be able to donate corneas or tissue but check with your team. Some young people and parents choose to donate their child's brain or whole body for research into future cures. It's important that you organise this beforehand so speak to your team and make your wishes known as soon as you're able.

## Is there any paperwork I need to think about immediately?

If you are in hospital, a member of the medical staff will normally issue a medical certificate of death. If your child dies at home you should contact your community nurse or GP as soon as you feel ready. Your GP will visit you at home and will issue a medical certificate of death.

The certificate will state the cause of death in medical terminology. Once the death of your child has been certified by your GP you can contact a funeral director.

You need a medical certificate of death before you can register the death. Registering the death is a legal process which you'll need to do within a few days – you can find out more about this in the next chapter.

If the cause of death isn't clear, the doctors will not be able to issue a certificate immediately. A coroner will become involved and decide whether a post-mortem is needed. A post-mortem is a medical examination following a death. It's unlikely that this will happen but if it does, it will delay the issuing of a medical certificate of death.

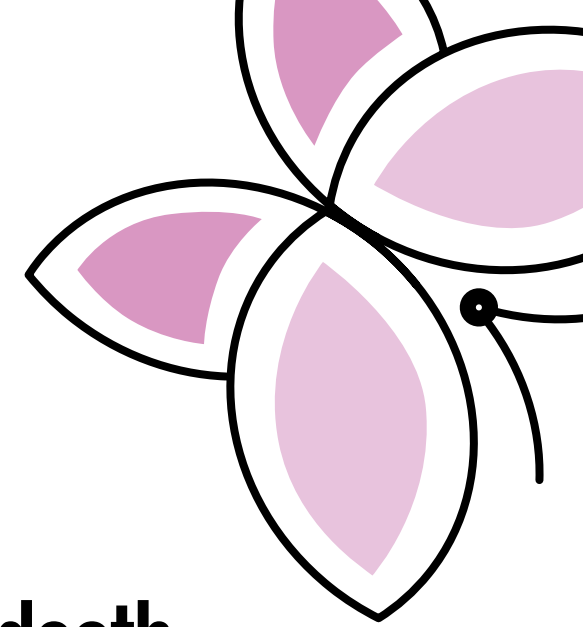


Sometimes post-mortems are used to understand more about cancer so that other children may be helped. Your doctor may talk with you about this but it can only take place with your written consent, unless the coroner has already decided that a post-mortem is necessary. Think about what feels right for you and your family before making a decision. If you consent to a hospital post-mortem in this way it will not delay the issuing of a medical certificate of death.

### **How do I take care of brothers or sisters?**

All sibling relationships are unique so your other children could react in many different ways. They might be very aware, not only of their own grief but of yours too, so may choose to keep their feelings to themselves. You're likely to know what they need more than anyone, but no one is expecting you to be superhuman. It might be a good idea to ask a close family friend or another family member to stay nearby who you know will be able to focus their attention on their needs.

You can read more about how children, teens and young adults grieve and what support they might need on the CLIC Sargent website.



## **Registering your child's death**

You'll need to visit the registrar that deals with births, deaths and marriages within five days of your child's death, or eight in Scotland. Although this is a devastating and surreal time, this process is a legal requirement so make sure you have the support to do it.

### **Arranging an appointment**

Most offices have an appointment system so call them first to check. You can register the death at any register office but if you go to the one in the area that your child died, you should receive the paperwork on the same day.

Either a doctor or the hospital will be able to give you the details of the nearest office. They'll also have given you a medical certificate of death and a 'Notice to the Informant' which you'll need to take with you to the register office.

## Getting support

If you decide to register the death yourself, it may feel daunting when you are shocked and distressed. Ask a family member or friend to support you, even if it's just to help you with practical tasks like driving to the register office and waiting with you. It usually takes about half an hour. Alternatively, the registration can be made by:

- a relative
- someone who was present when the death happened
- the person responsible for the place where the death happened (for example, the hospital)
- another resident in the same place
- the person who instructs the funeral director.

If there is no appointment system you can tell the registrar that you are registering the death of your child and you may be able to wait somewhere private.

## The documentation you'll need

The registrar will ask for:

- A medical certificate of death, signed by the doctor
- Details of your child's place of birth
- Details of your child's address.

The registrar will give you two documents:

- A Certificate for Burial and Cremation or the 'green form', which you can give to your funeral director
- A Certificate of Registration of Death

You'll be able to buy extra copies of the death certificate for a small charge. This price goes up if you want more copies at a later date so it's worth buying as many as you'll need at the registrar. They'll be useful for sorting out the practicalities and

will save time waiting for the original to be returned each time it needs to be sent somewhere.

They should also let you know about the Tell Us Once service and whether it's available in your area. If it is, they'll give you a unique reference number to use the service by phone or online – this will inform most government departments at the same time.

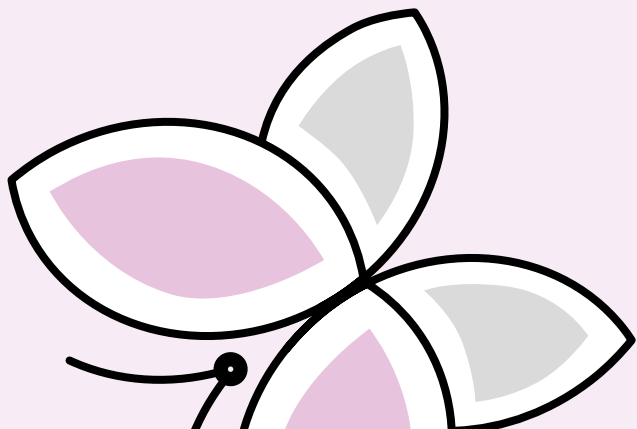
There are various organisations and government departments that you will need to inform when your child dies so that they can update their records. The Tell Us Once service will report your child's death to several places in one go and stop the benefits your child was receiving. The service is available in most areas of England, Scotland and Wales via the Department for Work and Pensions (DWP) or online by visiting [gov.uk](https://www.gov.uk). You can choose to do it online, face-to-face or by phone. In Northern Ireland, you can contact the Bereavement Service on: **0800 085 2463**.



# Planning your child's funeral

Facing the task of planning a funeral when you have just been plunged into shock can seem overwhelming. It's understandable that you might struggle to accomplish tasks in the way you're used to when you can't think as clearly. On the other hand, spending time organising could help you through these initial stages of grief. However you're managing, make sure you enlist the help of others and plan in a way that's right for you.

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## Your wishes as a family and planning the service you want

If you and your child talked about this together then they might have given you some direction about the type of day it should be. They might have asked you to play a song they loved or everyone to wear brightly coloured clothing. Siblings may well have their own ideas and want to chip in, so if it feels right, you could sit down as a family and discuss these ideas and use them as a basis to build on for the day.

Of course, you may not have had the opportunity to talk to your child about what happens after their death, or you made a decision not to. It can feel difficult to second-guess what you think they might have wanted but as long as you're making decisions that are right for your family and are done with love, then you are doing the best that you can.



## Where do I hold the service?

Services can be arranged in different settings. This might already be determined by your faith, but if not, you can choose for it to take place in a non-religious setting of your choice. This could be at a crematorium, a natural burial site, a hall, hotel or even your own home.

## Who will lead the service?

If you aren't having the ceremony in a place of worship, the service can be led by anyone. This includes family and friends, but many people opt for a celebrant. They will meet with you to learn about your child and help tailor a service that reflects their life and personality. A humanist celebrant will conduct a non-religious ceremony whereas a civil funeral celebrant can include religious material as well.

## What about the order of service booklet?

This booklet is given to people attending the funeral so they know what to expect and have a momentum to take away. It lists what's happening in the service and often contains photographs. They can be simple documents created at home or professionally printed brochures.

## How can I make it special?

There really are no rules when it comes to designing a ceremony so you should feel free to make it as personal and bespoke as you like. Incorporate wishes your child might have had, like the music they wanted or colours that people should wear. Think about things you could do to capture their personality and spirit. It could be balloons, decorations themed around a hobby they enjoyed, asking someone to make a slideshow with photos and video, calling on siblings and their friends to add their ideas too. Here are some things that other parents did to make it special and unique to them:

"I loved that a six year old's funeral stipulated everyone should wear his favourite colour of red; NO black. His young friends had all painted fabulous pictures for him that had been clothes-pegged to lines strung down the aisle and very young guests had pictures to colour within the order of service. Another mother wanted very much to speak but worried she would not be able to manage during the service, so she recorded herself at home in the days before reading out a favourite story. That was so beautiful."

**An excerpt from *Follow the Child: Planning and having the best end-of-life care for your child* by Sacha Langton-Gilks, mum of 'DD'**

"My son and daughter died within 12 days of each other, so we had 2 funerals within a fortnight. We wanted each funeral to be different, so they reflected the individuality of them both. They were at different schools and both their school choirs sang. We had their photographs on display boards as you went in. We followed my son's coffin into the Church but decided to have my daughter's coffin at the front and friends were invited to come and place pink carnations on top of it. We had balloons and candles, and some of their favourite music playing which their sister helped choose. A dear friend of ours painted beautiful pictures which were placed on their coffins – a winged warrior for my son, and a beautiful princess with a tiny superman making their way to a white castle in the sky for my daughter. A lady from the cemetery laid beautiful flower heads on the earth so that my daughter's coffin was lowered onto a bed of flowers, which was a lovely touch."

**Sarah, mum of Tom and Hazel**

“Our daughter planned the whole funeral and my father-in-law and I built the coffin and did heaps of other stuff. She knew what was happening and what she wanted. The whole process of doing what she wanted, and being involved in doing it helped a lot, and made wonderful memories that we hang on to.”

**An excerpt from In our own words: Parents talk about life after their child has died of cancer**

“We never spoke to Zac about this sort of stuff before he died so a lot of it was guess work. We just had to make the best of it. We ended up having a celebration of Zac’s life at our local rugby club with about 700 people and had a hog roast because Zac loved hog roasts.”

**Jason, dad of Zac**

### **Preparing siblings and yourself emotionally**

If you have other young children who want to attend the funeral they may need some explanations and preparation so that they will know what to expect. You could ask a trusted adult to keep a watchful eye over them and reassure them that there is someone to turn to during the day if you are not available to them at any time.

For older siblings, make sure you keep an open channel of communication and involve them as much as they want to be.

The day of your child’s funeral is likely to be both physically and emotionally exhausting. If you are worried about how you will manage think about talking to your GP or CLIC Sargent Social Worker.



## **Organising the funeral**

The experience of organising your child’s funeral, or celebration of their life, should be in line with your needs and wishes as a family. You should have as much support as you need, or feel enabled to do it all yourselves. You might want a traditional ceremony or you might want to make it as bespoke as possible – all these things should be possible.

### **What does a funeral director do?**

The experience and knowledge of a good funeral director can lift some of the weight of arranging practicalities and can be the easiest option at a difficult time. They can look after as many elements as you like, such as moving and caring for your child, providing you and your family with emotional support, arranging transport, helping to make special requests happen and processing paperwork. They should listen to your wishes and can support with as much or as little as you need. Most are on call 24/7.

On your first meeting, they will ask questions about all sorts of different things. Some of these choices might seem very insignificant compared to the devastation you feel. Or some might feel terribly important and not something you can decide on-the-spot. You don't need to have all the answers. If you're not sure – say you need some time to think about it. It's also good to know that often you can meet in the comfort of your own home, which can help a little.

Find the details of a funeral director who is a member of **saif.org.uk** or **nafd.org.uk** – these organisations have codes of practice and must give you a price list when asked.

## **I don't want a traditional ceremony.**

### **Are there alternatives?**

If you'd rather not go through the motions of a conventional funeral, you can choose a direct cremation or direct burials. This is when your child's body is collected and cremated or buried during working hours without a ceremony. You can request to have their ashes afterwards.

You are then free to arrange a memorial service when you're ready, perhaps to scatter ashes somewhere or organise an event where the focus is on your child's life. It's also a more cost-effective option.

You could also organise a unique service, with or without the help of a funeral director.

## **Can I do it myself?**

Many people aren't aware that you are under no obligation to use a funeral director. You can do it all yourself – the only legal requirement is that the death is registered and the body buried or cremated. It's still viewed as an unconventional option but for some, it can be an important process and very special way to say goodbye.

The Natural Death Centre has lots of in-depth advice about how to do a 'DIY' funeral – from leading the service yourself to private burials.

## **Burial or cremation**

We spoke to some bereaved parents who reflected on the choices they had made. One mum moved to a different part of the country years later and now lives far away from her child's grave. A dad chose to scatter his son's ashes abroad because he feared he and his family would feel obligated to visit a grave too frequently. Another parent said she felt pressured into a cremation while she was in a vulnerable state but actually would have preferred a burial and somewhere to visit. So think carefully about what might be right for you as a family but remember that there are no wrong choices – you can only do what you feel is best at the time.



## Burial

If you decide on a burial, you can visit local cemeteries and choose the one that is most suitable. The cost of this can vary hugely throughout the UK. Most prices will include the plot and burial but there may be extra fees for maintenance, or for someone who didn't live in the same district or borough. You could consider a natural burial ground such as woodland which is often cheaper and can be beautiful, peaceful spaces. It is also possible for a burial on private land, although this does need careful consideration.

A burial can form part of the service with everyone attending or you can keep it private with only close family, or a direct burial where no one is present.

Bear in mind that you may have to adhere to certain rules depending on where you choose to bury your child.

“In our experience church burials are much stricter in their rules and regulations than cemeteries which are usually run by the local authority (we hadn't realised there was much of a difference between the two). Hannah had a church burial and we found that there were significant restrictions in what we were permitted for her headstone – had to be certain colour, certain shape, no photos, no bright lettering, no symbols and we were accused of our wording not being 'religious enough'! We were also told that we couldn't have a headstone within the first six months as it would be 'too soon' to make a choice. Cemeteries seem to be more relaxed or flexible in their rules, especially having seen the headstones of some of the other children whose parents we know. It was just something we had never even considered before.”

**Simon, dad of Hannah**

## Cremation

If you are having a service in the crematorium, you can ask for a 'committal' at the end of the service. This is where the coffin is hidden from view by curtains or taken away. Instead, it could remain on view, or to be out of sight for the entire service.

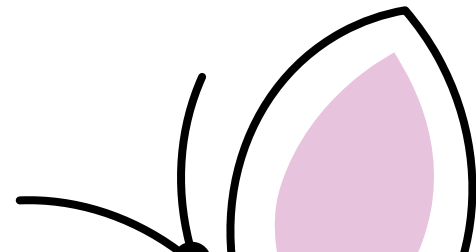
You can then arrange to have the ashes buried at the crematorium, scattered in the garden of rest or collect them to scatter in special place. Or you could keep the ashes with you at home. Whatever you choose has to be right for you and your family.

## After the funeral

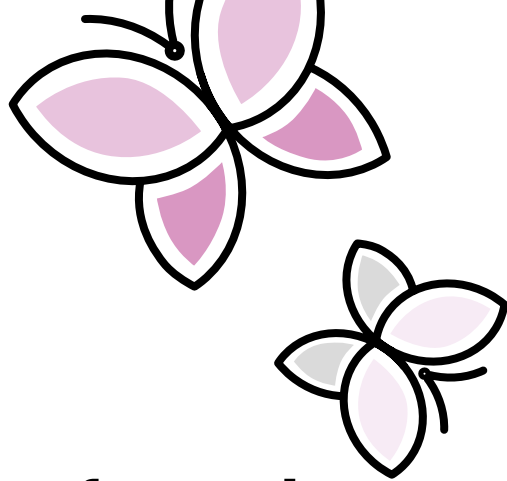
If you're having a ceremony, a get-together afterwards can bring together family, friends and people from your child's community. It gives people a space to share stories and talk together following the funeral. You could:

- Make arrangements to meet at a local hotel, a place of worship or community venue and invite people to attend the funeral. You can then choose whether you wish to go.
- Arrange for people to come back to your home. You may like to think about asking a friend or family member to be responsible for asking people to leave when you want to have time alone.

Your family and friends will understand that you need to do what is right for you, even if this means that you prefer to have time for yourself without making any special arrangements for others.







# Paying for a funeral

We know that the cost of a funeral can be an additional source of worry for many parents. There are things you can do to help reduce the cost.

It's completely understandable that you would want the easiest experience and best choices for you as a family. It's also reasonable that you would want to make your child's funeral as special as it can be, without needing to cut corners in order to save money.

## What help might be available

In April 2018, the Prime Minister announced a Children's Funeral Fund for England for grieving parents who have lost their child. Under the scheme, parents will no longer have to meet the costs of burials or cremations. Fees will be waived by all local authorities and met instead by government funding for parents of children up to the age of 18. The Scottish government also agreed to remove local authority charges for under-18s. We will update the CLIC Sargent website with more information as details are announced.

In Wales, child burial and cremation fees were scrapped in 2017. In Northern Ireland, although many councils make exemptions for children's funerals, you may still need to meet these costs.

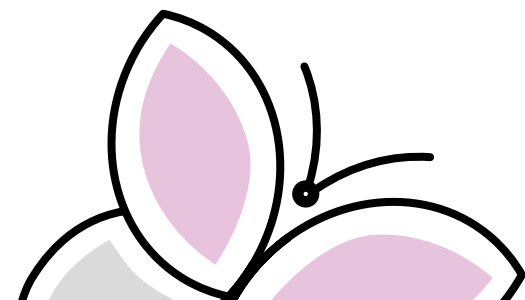
If you do have to pay, funeral directors will sometimes be willing to accept payments in instalments if you can't afford the fees upfront – so it's worth asking. Some charities, such as the Child Funeral Charity, offer financial assistance to families who need help. Many funeral directors, clergy and celebrants do not charge any fees for a children's funeral. Co-op Funeralcare has a free child funeral policy which provides basic support to bereaved parents of children up to the age of 18. Or, you might be able to receive a payment from the Government's Social Fund if you are claiming certain benefits.

## Government payments

A Funeral Expenses Payment can help with 'necessary' or 'reasonable' costs. It won't cover the whole bill but it can help towards things like travel, burial or cremation fees, the death certificate, directors' fees, the coffin or flowers.

You or your partner will need to be claiming certain benefits to be eligible for a Funeral Expenses Payment. You can find out more about applying in our booklet Practical tasks after your child dies, or at [clicsargent.org.uk](https://www.clicsargent.org.uk)

CLIC Sargent offers a compassionate grant to families where a child has died, to help towards funeral costs. Your CLIC Sargent Social Worker can apply for this on your behalf.





# Helpful resources and organisations

## For caring for your child

### Children's Cancer and Leukaemia Group

CCLG has in depth information on their website about coping with common symptoms and general care including nutrition, alternative and complementary therapies and relaxation techniques. They also produce a booklet called Managing symptoms at home which gives information on specific symptoms. You can order or download it for free from [cclg.org.uk](http://cclg.org.uk)

### Together for Short Lives

This charity has free resources available from [togetherforshortlives.org.uk](http://togetherforshortlives.org.uk) including the leaflets Making critical care choices for your child, Care planning in advance as well as FAQs. You can also call their free helpline on 0808 8088 100 if you have a question or need support. The helpline is open between 10am and 4pm, Monday to Friday, or leave a message.

## For talking to your child

### Gentle willow: A story for children about dying by Joyce Mills

Written for children who may not survive their illness, this touching tale helps address feelings of disbelief, anger and sadness with love and compassion.

### On the wings of a butterfly: A story about life and death by Marilyn Maple

A story about a young cancer patient who finds comfort in her friendship with a caterpillar; as the caterpillar prepares for transformation into a butterfly, the two share their fears about the unknown.

### Water bugs and dragonflies by Doris Stickney

This uses the example of a water bug's short life under water as a person's time on earth, before emerging as a dragonfly after death. Children can understand this idea of leaving the old body behind.

### Always and forever by Alan Durant

A story about Fox and his family that reinforces the power and importance of remembering.

### Fred by Posy Simmonds

A story book about a beloved pet cat who has died.

### I'll always love you by Hans Wilhelm

A little book with a tender story that can be used as a conversation starter.

### No matter what by Debi Gliori

A heartfelt story about the unconditional love each parent feels for their child.

### The mountains of Tibet by Mordicai Gernstein

A story of a Tibetan woodcutter who embarks on a new journey after death for children aged 7 and up.

### **Up in heaven by Emma Chichester Clark**

A story about a little boy's dog that may help children to discuss their views and ideas about heaven.

### **Living your life with a terminal diagnosis by CLIC Sargent**

This booklet for young people aged 16 and over explores emotions, gives tips on talking to people and links to resources for more support.

## **For talking to siblings**

### **I miss you: A first look at death by Pat Thomas**

An illustrated book to help children understand that death is a part of life and helps them to express their feelings. 4-7 years

### **When someone has a very serious illness by Marge Eaton Heegaard**

This workbook allows children to put their thoughts and feelings into words, helping families to communicate. 9-12 years

### **Michael Rosen's sad book by Michael Rosen**

Illustrated by Quentin Blake, this book is about love and loss, explaining grief in a way children can understand. 5-7 years

### **Help me say goodbye: activities for helping kids cope when a special person dies by Janis Silverman**

An art therapy and activity book to address questions and fears children may have when someone is dying.

## **For planning**

### **Follow the child: Planning and having the best end-of-life care for your child by Sacha Langton-Gilks**

Sacha is a parent of child who died from cancer in his teens. She gives her perspective about what to expect and what she found helpful. Specialists also share their expertise and the book offers practical advice.

## **For preparing and supporting yourself**

### **Rainbow Trust**

Support for families who have a child aged 0-18 years with a life threatening or terminal illness and need bespoke emotional and practical support, including with siblings, at home or in hospital.

[rainbowtrust.org.uk](http://rainbowtrust.org.uk)

Call 01372 363438 or email [enquiries@rainbowtrust.org.uk](mailto:enquiries@rainbowtrust.org.uk)

### **BACP – It's good to talk**

This is a database of therapists accredited by the British Association of Counselling and Psychotherapy (BACP). Therapists on the register have specialist skills and knowledge and have undergone relevant training and supervision. You can search by area, by therapy need, by type of approach or by therapy offered in languages other than English.

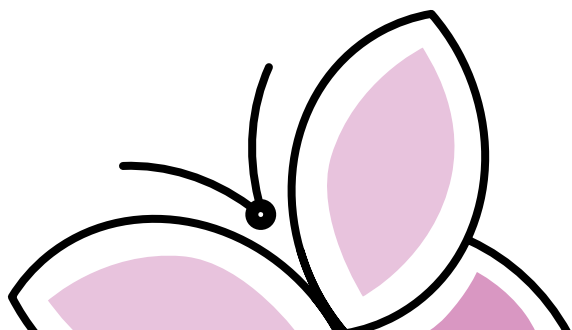
[itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)

### **Mind**

Advice and support to empower anyone experiencing a mental health problem, Mind supports people across England and Wales through supported housing, crisis helplines, drop-in centres, employment and training schemes, counselling and befriending.

Call 0300 123 3393 - 9am to 6pm, Monday to Friday (except for bank holidays) or text 86463

[mind.org.uk](http://mind.org.uk)



## **Samaritans**

Samaritans volunteers are available 24 hours a day, 7 days a week to provide confidential support on any issue. They can be contacted by phone, email and letter, and also offer face-to-face support at local branches across the UK. They offer a safe place for you to talk any time you like, in your own way – about whatever’s getting to you. You don’t have to be suicidal.

[samaritans.org](http://samaritans.org)

Call 116 123 free anytime or email [jo@samaritans.org](mailto:jo@samaritans.org)

## **For organising the funeral/celebration**

### **Natural Death Centre**

Providing support, advice and guidance for planning a funeral, the Natural Death Centre Charity is here to share knowledge and empower everyone who wants to have the best experience possible when it comes to making arrangements for a funeral.

[naturaldeath.org.uk](http://naturaldeath.org.uk)

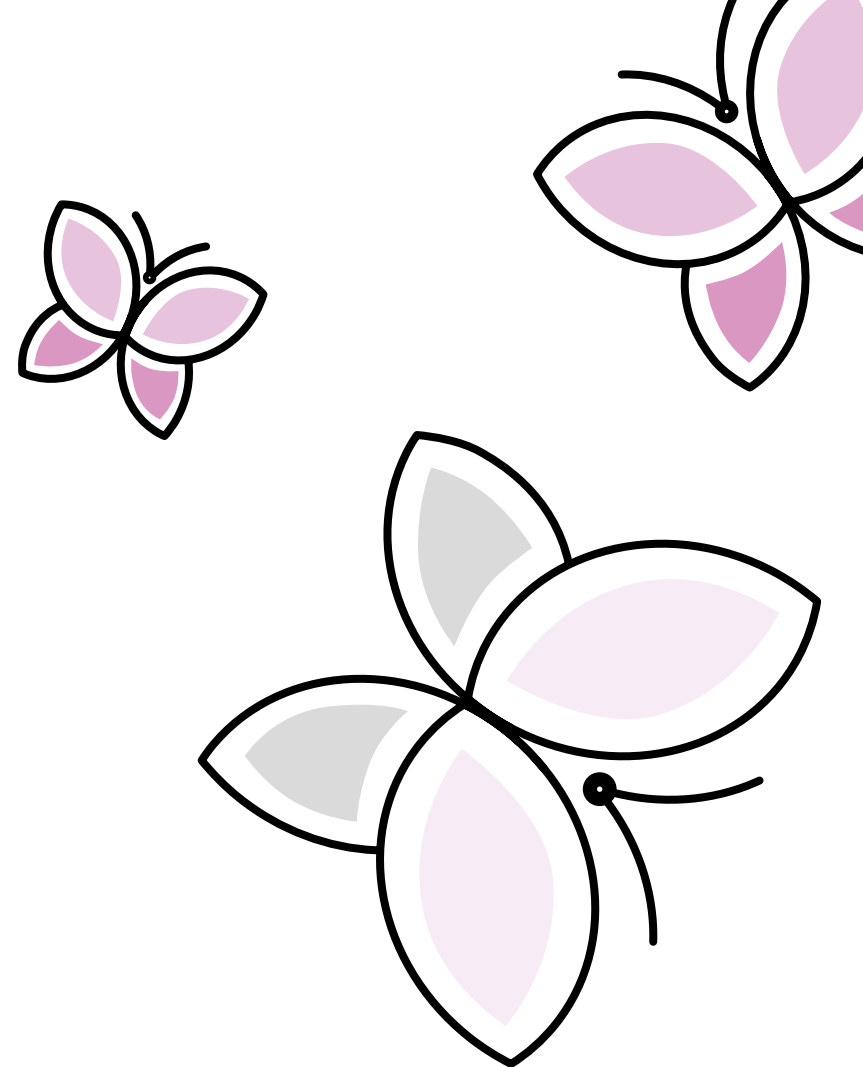
Call 01962 712 690 or email [rosie@naturaldeath.org.uk](mailto:rosie@naturaldeath.org.uk)

### **SAIF / NAFD**

The National Society of Allied and Independent Funeral Directors are committed to ensuring that the funeral professional maintains high standards. The National Association of Funeral Directors provides support and guidance to funeral firms and bereaved families in their care. When choosing a director, make sure that they are listed as members of one of these organisations.

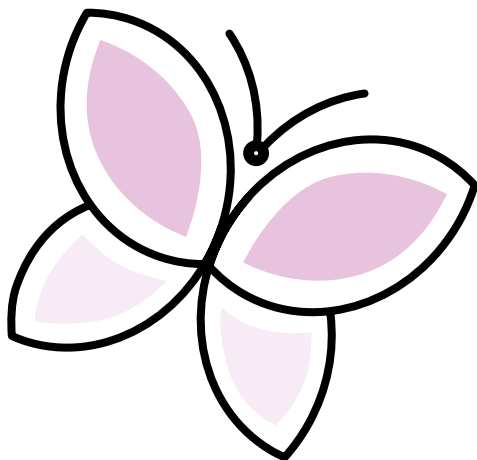
[saif.org.uk](http://saif.org.uk)

[nafd.org.uk](http://nafd.org.uk)



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