



Facing the death of your child

Suggestions and help for families, before and afterwards

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On 1 August 2006 the UK Children's Cancer Study Group and UK Childhood Leukaemia Working Party merged to form the Children's Cancer and Leukaemia Group (CCLG).



Foreword

The death of a child is one of the most painful and devastating experiences that families can face. When a child dies, it simply does not make any logical sense. We do not expect to outlive our children. It is not the normal way of things. Suddenly, all the promise of that young life has gone. The sadness and grief can be overwhelming and it can feel as if nobody understands your pain and you are isolated in your own private world of agony. We, a bereaved parent and a psychologist, have jointly written this booklet to try to help with both practical and emotional issues.

This booklet will try to convey what we, and other parents and professionals, have found to be helpful or unhelpful at this very difficult time. We could not address all cultural, ethnic, spiritual and religious points of view, and acknowledge that this booklet is largely written from the Western perspective.

The booklet has been designed in sections, which you can read at the right time for you. Each chapter has an introduction and a summary, so you can have enough information to help you choose when and if you want to read that chapter. We have also included two sections you may want to give out to friends or to your child's school. At the end of the booklet is a list of support available, contacts and a booklist.

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Bereaved parent

I will never forget the day the doctors told me that my son had cancer.
I will never forget the day the doctors told me that there was no more
that they could do.
I suppose I felt that while there was treatment, there was hope.
I could say that the doctors were trying to make him better,
even though they had also said that it was not going to work.
I had to accept that he was not going to make it.
I had to find a way to tell my other son.
How do you explain a thing like death to a seven year old?

Tina Clay



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Parents – preparing yourself

In this chapter, you will find some ideas that you may wish to think about when you are trying to face the fact that your child is probably going to die. Knowing what has helped other families in a similar situation, may help you find your own way of facing this difficult time. We cover some of the worries other parents have experienced and offer suggestions of how to answer some of the more difficult questions.

The approaching death of your child is likely to be the most difficult time in your life. Although it feels impossible and you may feel your heart is bursting, parents, brothers and sisters and other family members learn to live with it as best they can. Other families have said it is not so much coming to terms with it, as living with what is happening. You will always be your child's mother or father, and your other children will always be a brother or sister. Some families might feel that acknowledging that their child is dying is a sign that they are giving up. Others want to be prepared and get their affairs in order.

Everyone is different, and will cope in their own way. People can go through stages of grief and preparation, but it is individual and not always in the way people imagine. Although it is often felt that difficult times can bring a family together, it can also

create divisions. This sometimes happens if one parent has been more involved in their child's care. Then, parents might be at totally different stages of understanding and preparation.

How can I prepare myself?

It can be helpful to think about what experience you and your family have had of death in the past. Other experiences of death may have been very different from the enormity of losing a child. However, they may help you to recognise ways you coped before that may help you now. Try to see what is happening, not only from your point of view, but also from that of your child and their brothers and sisters.

Planning what to say and what to do can give you some purpose and direction. There may come a time when you will be left alone with your thoughts. Some people have found that talking or writing their feelings down, can be helpful.

"I tried to plan what I would say to other people. It worked some of the time. Sometimes, the actual planning was enough for me to feel I could get through this ... something to say, something to do..."

Mother of an 8 year old boy

Just as your feelings change at this time, so will your goals for life. When children are still having treatment, a day-to-day existence is all many people can cope with. When a child is near death, hopes change and it is a struggle to get through each hour. Some parents say that everything is so different. All values can change and what is so important is giving love and comfort to the dying child and the rest of the family. Some parents have nightmares and dreams about their child's death where they may say, for example, "How will I cope?"; "Am I strong enough?" These can be a subconscious way of rehearsing and preparing you for what lies ahead.

Spiritual questions

We all have spiritual questions at one time or another. You do not need to have a faith to ask deep and meaningful questions. These thoughts are natural. We belong to a multi-faith and multi-cultural society. When someone we love dies, this may raise difficult questions. We may feel confused and bewildered whatever our upbringing, cultural, spiritual and religious background.

People often say that they feel angry with God or that they do not believe in God and question how can this be allowed to happen. Alternatively, other families have felt that their beliefs can be a great support at this time.

It is often when something as traumatic as illness or death happens that all these

feelings are brought to the surface. Questions arise such as "What does this mean?"; "Is there a meaning to life?"; "How can I possibly make sense of all this?" or "Does life have a point any more?" It would be impossible to give answers to all these questions. You may wish to talk to friends, staff at the hospital, the hospital chaplain or a local religious leader. Some people may feel embarrassed about talking about these things but it can often be very valuable.

What have other parents worried about?

Many parents worry about their own life and survival and about the time remaining, or that their child may be in pain. Staff will always offer the best possible pain control. This is usually effective without the child being sedated. Staff understand how important it is for both child and parents to be able to say important messages to each other at this time. It may be useful to remember that children may be able to hear when too sleepy to respond, or are sedated. They may also be able to feel touch and cuddles, which can be comforting.

"The most important thing was to be able to cuddle my child at the end. If I couldn't do that I would have felt a failure as a mother, and I could actually only do that when she was sedated."

Mother of a 17 year old girl



How much time your child has left is difficult for doctors to predict. Often it seems there is not enough time to say all that needs to be said. Children with terminal leukaemia may die within a few weeks. Children with brain or other localised tumours may live for a few months, but this can vary enormously.

It is only when a child is within days or hours of death that the amount of time left becomes clearer and can be predicted more precisely. Until this point, it can be hard to believe that it is actually going to happen.

What is right for one family will not necessarily be right for another. The desire to make everything perfect is so strong that this in itself can cause worries and extra pressure for the family.

Parents are in an impossible position. While trying to care and anticipate the needs of their dying child, they can feel guilty and torn in many directions about not being able to meet everybody's needs. It can be a tremendous strain on relationships and some parents find it useful to ask for some outside help. Professionals cannot always recognise families' needs, so if you feel that you need support, do ask for it (see page 58 for details of where to get support). It is hard for people on the outside to know when the time is right to offer help. If you are offered support and it isn't the right time, it's OK to say no. It is also OK to ask for help when you feel that it is the right

time. Saying no does not mean that you will not be able to receive help later on.

Caring for your sick child can be very hard work, physically as well as mentally. It can put almost intolerable strain on parents. One mother described her great feelings of guilt when she almost wished the inevitable event to happen, because she wasn't sure how much longer the family could cope at home.

Parents worry about how they will cope; most families will find the best way for them. Some families, when thinking back, are surprised at the strength they found and how they got through this time.

"I thought we would all crack up, it all seemed so horrific...As time passed, we found ways to cope, things to spur us on, little things to grab onto, to focus on... I was amazed how we did cope, maybe we just had to."

Mother of a 3 year old boy

Good practical support from professionals may help to relieve the stress and help families find ways to manage.

One parent families

If you are a one parent family, you may have already coped with the diagnosis and treatment on your own. You may already

have developed good support systems. There may be financial implications if you cannot work. Advice and support, both financially and emotionally, can be offered at the hospital and at home.

If plans have been made for your child to die at home, the idea of being alone with them when they die, or alone with your other children, can be frightening. The responsibility can feel overwhelming. Some parents doubt their ability to judge what is happening and when to ask for help. In some cases, family or friends may also help. As much preparation as possible in advance, with the hospital and community team, will help to reduce your worries. Support is always available for you through the hospital or community teams.

Many couples who are divorced or separated can work together, particularly if the other partner already sees the child. However, this is not always possible. Not all couples can work together and old wounds may be re-opened and trust lost. Talking these issues through with a friend or health professional can be helpful. Then everyone is clear about the level of involvement your former partner will have. You may want to consider the following questions:

- Does (or should) your former partner know about your child's illness?
- Do they still have parental responsibility?
- Do they still want to be involved?

- Does your child want to see your former partner?
- If your child does want to see your former partner, the hospital or social workers can advise and support you in this.
- If you are planning to care for your child at home, are you prepared for your former partner to visit and help?
- Have you discussed this with the hospital staff?

Step families

Many step families also find themselves in awkward situations. Step parents may ask themselves where they fit in. When a child is dying, issues of who will play what role will be raised. It can be a time of important questions and difficult answers.

What questions might you be asked?

It can be helpful to think about and anticipate questions you might be asked. It is perfectly alright to say you do not know the answer. You may want to say that you will think about it and try to answer later on when you have thought it through or have talked to someone else. There really are not any right answers, just ones which are right for you and your family. Other families have found the suggestions below useful.

Questions from the sick child:

“Why do people die?” Dying is a natural part of life, all living things will die, time or



illness wears out important parts of our bodies and they can no longer work.

“Why can’t the hospital stop someone from dying?” They do sometimes and always try their hardest, but sometimes they can’t make someone better.

“Will you be able to hear me?” I hope so, it is hard to say, but you’ll always be in my thoughts and dreams.

“Will I still be able to see you?” I hope so, no one really knows, but I’ll always remember what you look like. If you close your eyes you can get a picture of me in your head, like I can of you. Even if you can no longer see me, it doesn’t mean I am not there.

“I’m frightened.” I’ll be there with you, looking after you. (It is important to make the child feel safe, by surrounding him or her with favourite things and people to cuddle touch and smell, and feel surrounded by love).

“Is this really happening to me?” Yes, it is happening to all of us, we are in this together as much as we can be.

Questions other people might ask:

“Where do dead people go?” Some people believe they go to paradise, or heaven, where there is no pain and it is peaceful and happy. Some people think you come back to earth.

“Why is someone I love dying?” Sometimes life is just not fair. It was nothing you or anyone else did or did not do. Their body is just not strong enough to carry on living.

“How do I know they are really dead?” They will stop moving and breathing, and will be quiet and peaceful.

“Is my sister really going to die?” I hope not, but she probably will, because we don’t think she can get better.“

What about organ donation?

This is such a difficult issue to think about, but many families do want to talk about it. It is best to discuss what options (which are very limited) are available with your doctors or nurses.

Chapter in brief...

- There is no perfect way of coping – what is right for one family will not necessarily be right for another.
- You may find it helpful to think through and plan what you might want to say or do.
- A previous experience of death may help you with coping.
- Caring for your sick child can be very hard work physically as well as mentally.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.



Preparing your sick child

In this chapter, we suggest how you can start preparing and talking to your sick child about what is happening to them. It is difficult to decide how much you tell your child and when. We offer some ideas and words that have been used by other people. We also offer advice about how to start talking about death and dying. This includes some thoughts that children have when thinking about what happens after someone dies.

Be aware of your own limitations at such a stressful time and don't expect to always get it right. Remember that this is never a one-off conversation, more an ongoing process. The more open the communication, the easier it can be for a child who wants to talk. It may be useful to look at the section on children's ideas and understanding of death (page 18) to help you get ready for preparing your sick child and their brother and sisters. What you say will depend very much on how old your child is and what they already understand. Younger children will, of course, have a very different understanding of what death is than an older child.

How do I decide if I should tell my child they are dying?

No one can say what is right for your child and your family. Some parents are worried

about frightening their child. Children with cancer nearly always know they have a serious disease. Many know that you can die from it and may know of other children who have died. Some children who are dying start to distance themselves from family, friends and others. Their social world may begin to shrink. If parents can communicate both good and bad news in a way that makes their child feel safe, then the child will feel comforted. They will also believe that mum and dad will help no matter what happens.

"It was a really difficult decision. We (parents) decided that as we had been honest all the way through, we would tell him that he was going to die. It was very difficult but he told us he was glad we were truthful. Then we all sat down and sorted out what he wanted to do and what his needs were. I will always cherish that conversation, as I felt at last we really were respecting him as a teenager."

Mother of a 17 year old boy

Parents sometimes feel under immense pressure to tell their child that he or she will die, or indeed NOT to tell the child. Whatever you decide needs to



feel comfortable for you as a family. It is important to be able to let your child know they can ask questions and to remember that often children feel they need permission to talk about death. Try to see it from your child's point of view:

- Has he or she been able to raise the subject?
- Do you avoid the subject?
- Are you not letting him or her talk about difficult subjects because they are too painful for you?
- Are you asking the right questions?
 - what do they think is happening?
 - is there anything they are worried about?
 - what do they think is going to happen?
 - is there anything they have not been able to ask, but want to?

Not all children or teenagers want to talk about the fact they are dying, but some definitely do want to talk about it.

Some cultures forbid such open discussion. Other families just cannot talk about death because it is too painful or totally outside their experience. Remember that for some dying children it can be hard for the child if the parent remains silent. Silence from a parent can be seen as a barrier to talking, even if that was not their intention. Young children might have fears or fantasies about

what is happening. It may be useful to ask yourself what your child will imagine is happening if they are not told they are dying?

"He suddenly stopped asking questions. He would go quiet and change the subject if we began to talk about what might happen next..... Lots of people tried to talk to him. In the end he just got cross and shouted 'I don't want to talk about it'..... He didn't want to talk about it and once we had stopped trying to ask about it, he was much more settled. It worked for us, even though we know it won't work for everyone like that."

Father of a 14 year old boy

How do I know what they already know, and what they want to know?

It may be useful to talk with your child about what has happened to them so far. You could ask what they think is going to happen to them, or if there is anything they are thinking or worrying about. Often this can lead into: "Am I going to get better?" At this point you might say, "The treatment doesn't seem to be working any more and we think you might not get better". Ask your child if they would like to talk about what may happen next, or if they have more questions. This is an incredibly difficult and painful discussion to have and it may never

take place for some families. Often it is easier to have this type of conversation while you are doing an activity. A child has the right to be told if they have a wish to know. Remember that some children may not want to talk about this with their parents, but may talk with other people. Try to offer your child plenty of opportunities to have this sort of conversation.

There are some very good books and booklets which can be a good way of opening up conversations (see booklist on page 60).

What do I tell my child?

Most children will already have been told about the cancer and treatment and know that it is serious. They will sense that something has changed. Suddenly lots of other people start to visit and people who always visit start to come more regularly. You may also look and act differently, no matter how well you try to disguise it. Children are very good at reading faces, expressions and body language.

Everyone is scared of saying the wrong thing. Generally, it is better to be as honest as possible. Try to agree on what to say, to avoid giving your child confusing messages.

One eight year old girl needed to talk about her wish to go to heaven so she could wear her special wings. That conversation helped to comfort that little girl and make her feel safe. It also helped her mum to understand what

her daughter thought was going to happen.

Other children need to have information given out a bit at a time. This allows some time for the information to sink in and they can check what is happening. A bit at a time helps some children feel that they are in control and can choose either to carry on talking about it or decide they have had enough of talking.

"My lovely daughter actually wrote on a piece of paper, am I dying? She couldn't talk but I could explain to her. I said, 'yes, we think you are not going to get better this time and that you will die.' I couldn't believe it when she actually wrote back, 'Thanks for telling me, that's what I thought too.'"

Mother of a 16 year old girl

How do I tell my child?

Hardly anybody feels they do this perfectly. You will know best whether to talk to your child on their own or together as a family. Don't be afraid to cry. Your tears can't make them any more upset and can give them permission to cry too. Choose a time when they feel safe and comfortable and when they have shown that they want to know what is happening. Give out small bits of information gradually. You may need to repeat part or all of it.



"My brave, brave son asked me, 'Am I getting better, 'cos the chemo has been stopped?' I told him, we have stopped the chemo, because it is not working any more.... A few days later he asked me 'Does that mean I could die?' and together, his mother and I sat down and told him 'Yes it did'. I never want to go through that talk again. I thought I was going to be sick. Again, a few days later he came and asked a bit more. It taught me how he really needed only a tiny bit of information a bit at a time. It made it much easier for all of us, in a sad kind of way."

Father of a 10 year old boy

Try and keep the conversation short and be prepared to come back to it later when your child wants to. Use simple words that you know they will understand, and stop when they or you have had enough. Some children react immediately; some act as if they did not hear what has been said; some want all the information at once and some clearly only want a little bit of information. Encourage them to ask anything they want and let them know that you will be with them every step of the way. In this way, you are giving them permission to talk and to take the conversation further if and when they wish. You know your child best, and will be able to tell when they have had enough

talking. Your child will feel that you respect them and that it is okay to stop then and to talk again later.

What will we talk about?

At this time, it can be really supportive to use words and examples from your experience of others who have been ill and perhaps died. Religious examples or familiar stories may be helpful.

Your child may want to feel safe and to know who will be there when they die. If talking about death is brought out in the open, it can be an opportunity for the child to say goodbye and do the important things that they want to do. Some children may want to plan their own funeral. They feel it is their way of saying goodbye and to make known their last wishes.

"I planned with my mum and dad, that all my mates and family would hire a big party bus. I'd lay on all my favourite booze, food and music, and then they could have a good time. I knew that even though they'd be sad, at least it was what I would have wanted to do, even if I wasn't there."

18 year old boy

It is important not to feel pressured at this time to do anything against your or your child's wishes or beliefs.

Once a conversation about the possibility of dying is started, there is an opportunity to talk about many things. For example, what they think is going to happen, their feelings and thoughts about death, afterlife, heaven, God or angels. It is important to let them describe what they think is going to happen. It is what they believe that matters.

What do children think happens after death?

Children tell the most amazing stories about afterlife and the places where they think they may go:

- “I am going to be a fairy and float around granting wishes, you know, with glittery wings. I know it isn’t what you’d expect a 17 year old to be but fairies are special and can sprinkle magic dust. That is what I am going to do if I die.” *17 year old girl*
- “I am going to be a guardian angel and look after my mum. I’ll always be there to show her that I love her and always will.” *7 year old girl*
- “I think life just stops. It’s over, so what; there is nothing wrong in that. Maybe once we’ve had our time, it just leaves more space for others to fill in the gaps.” *13 year old boy*
- “I’m not going to disappear, things just don’t stop. I think I’m going to go and be a star trek captain and fly

the skies. Maybe if everyone looked hard enough they’d be able to see my spaceship.” *8 year old boy*

- “I think there is an ether surrounding the world, filled of all the wisdom and feelings from people who have died. It helps those left behind, as it is a comfort to know it is there and protecting the world.” *18 year old boy*
- “Paradise, it exists. I’m going to go there and wait for my family. I know we will meet up again, I just wish we could all be together for ever.” *15 year old girl*
- “I know where I am going, I’m going to God and I’m not going to be in pain anymore.” *14 year old boy*

How can I explain dying?

Try not to use euphemisms such as ‘pass on’, ‘pass away’, ‘go to sleep’ and ‘lost’. They do not help a child to tell fact from reality, and can be confusing for children. Death is seen and talked about on television and in films. Children are probably best told while being cuddled. Touch is very important and comforting. You may find it helpful to use a book (see the booklist on page 60) to explain death. For example, Doris Stickney’s *Water Bugs and Dragonflies*. 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. When you



die, the body does not work anymore and that there can be hope and beauty after death. Using some of the workbooks “When someone is very ill” (see page 60) can be an excellent way of opening up conversations whilst drawing and writing, and can make it easier for your child to start talking.

Many children just want to explore that when someone dies they will go to heaven, a beautiful place. For some, this means becoming an angel and for others, living on a cloud. Depending on your religious and spiritual beliefs, the idea of heaven or an afterlife can help a child feel safe. It can be difficult to understand, so be prepared for further questions. Lots of parents and children talk about heaven as a safe place. There, they will meet others who will look after them and the rest of the family.

Another metaphor often used, is of a caterpillar. This represents the healthy person who, when they become ill, develops like a caterpillar into a cocoon. When their body does not work any more and dies, the cocoon is shed and the butterfly (like the soul) flies off somewhere else.

An image of the child in a sailing boat, sailing towards the horizon may be helpful. The child sails further and further away, until they can no longer be seen. You know they are there and they know that you are on the shore watching, waving and loving them.

You could explain that bodies stop working. Go slowly. Explain that when you die, your

body doesn't work any more, it can't get better; you don't breathe, can't eat or drink and will not be in any pain. This can feel very final to explain to a child, but remember that some children are looking for a biological explanation. Some parents find this impossible to explain. At these times, it might be useful to use another adult to help talk this through.

For active children, an active metaphor can help. A 10 year old boy worked out that dying is like being a space rocket. In life it is full of energy and it combusts. You can see flames and it shoots out from earth, then slowly it slows down. The first section disengages and falls away, then the second part, getting smaller and smaller so there is only a little part left. Then it disappears so all you can see is a trail in the sky. Then even that disappears. You know it's still there, even though you can no longer see it.

What if my child has nothing that they believe in?

Children and teenagers often have their own theories which may not fit in with any particular religion or philosophy. They need to know that you really are listening to what they are saying. Some children find it impossible to believe in anything, and may ask you for your beliefs. This can be an ideal time to explore together what you both understand and feel. Your knowledge and experience can help them to feel safe. Some children believe that life just stops.

It is important to listen to their views, and to try to understand why they think that.

"I couldn't bear it when people tried to tell me what I should believe. Just listen to what I feel. I don't judge others, why should they try and judge or influence me, especially now."

15 year old girl

How do I know what my child is really asking?

It is useful to ask your child what they really want to know, as understanding the question will help you to answer. You can reassure them that you will reply as best you can but that you won't always have the answers. It's OK to say that you don't know the answer. You hope that dying will be as peaceful as possible and whatever happens, they will be with people that love and care for them.

If your child asks "What is going to happen?" it may be a sign that they need to talk about what they think might happen. They may not necessarily be asking for your views. Do they want you to tell them what **you** think, or do they want to say what **they** think is going to happen?

One young boy got very upset and eventually was able to say that he was scared of being in heaven all on his own,

waiting for everyone else. We then talked together with a vicar, who told him that in heaven, time is on a different time scale.

In heaven, time passes in a flash and then everyone is together. On earth, time is much slower. He found this very useful and said that he wasn't afraid of dying.

If the child or teenager believes in heaven or afterlife, they may find this comforting. Sometimes they feel there is nothing. If this is the case, it is important to just listen. Ask them what helps, as trying to impose your beliefs when they may be in despair, may not be helpful.

What if my child does not want to talk?

If your child does not want to talk to you, remember that it might not be the right time, in the right place, or even with the right person. Talking about such a difficult subject may be possible later or with someone else. Some children never want to talk about it, which may be their way of coping. Giving children the chance to talk, will give them the opportunity to talk if they change their mind at a later date.

Some children may wish to collect special things together in a box (often called a memory box), to leave for others. Memory boxes can be very comforting both to make and for those who look at it after your child has died. Your sick child may like to collect special things or to write letters to give to



others. In this case, it can be very powerful to choose or make a special box with your ill child, to talk about what and why things are important. It can also be very moving to make up a memory box either for yourself or for your other children after your child has died. It can be a private, precious collection to cry over and to remember good times.

"My eight year old daughter made a special life box. We talked about and sorted through her favourite pictures. She put in some favourite stones and shells and all kinds of special things she had collected over the years. It became a little ritual to do every day. What goes into her special box? How shall we decorate it? I loved the box and filling it with her was something I will never forget. I may cry when I open it but we did it together and it's precious to all of us."

Mother of an 8 year old girl

What about school and how school can help?

When your child is so seriously ill, school and education can seem unimportant. To the child, however, any kind of normality can be a great distraction and really help them to cope. Schools usually want to help, however, they do not want to intrude on the family's privacy.

Your child may feel that they would appreciate some contact with the outside world but cannot manage a whole day in school. It may be possible to do part of a day, with a member of staff designated to take responsibility. Schools are usually helpful with these kinds of arrangements. These are easier at primary school level where your child will have one special teacher. At secondary level, there are often year heads or special needs teachers who can help.

If your child is too unwell to manage school at all, perhaps a short visit from classmates might be welcome, or a tape from them sending special messages. This could be monitored and organised by the teacher responsible. The chances are that teachers and classmates will have followed your child's illness from the start. This may make them feel involved and wish to help in some small way to make the last days special.

Having a liaison person at the school is essential. This should be someone you can be in contact with and trust to give out information in the way you and your family prefer.

Schools can also provide home tutors. These are trained teachers, who often have a special empathy for very seriously ill children and their families. They can become a good source of support.

Tutors usually tailor their sessions to how your child is feeling. They take into

account special interests and hobbies. Nobody worries too much about the national curriculum, but it may still be very important to your child to learn new skills like their friends are doing. If you would like a tutor and your child's school have not offered this, you can contact the school office or the local education authority. Staff in the school room at the hospital (or local home and hospital tuition service) may also be able to help. We have produced a handout that you may like to copy and give your child's school at the end of this booklet (see page 54).

What about my child's friends?

Most children like to remain in some sort of contact with their friends throughout their illness. It gives them a chance to talk about normal, and often silly things. They can be themselves and not just an ill person.

You may need to prepare friends for how your child is looking or behaving, or the fact that your child is very ill. Not all children want contact with others and you may have to act as a negotiator. Your child's friends may have different views, needs and desires to your child's. Sometimes, alternative non face-to-face types of contact work very well: e-mail and videos, MSN messenger, and either texting or speaking on the phone.

Chapter in brief...

- Don't expect to always get it right.
- Asking your child what they think is going to happen to them may help them to talk about it or ask questions. However, this won't be right for all children.
- While you may be afraid of saying the wrong thing to your child, it is generally better to be honest when answering questions.
- Whatever helpful advice you are given, only you know what feels right for your child and family.
- Give out small bits of information gradually. You may need to repeat part or all of it.
- It's OK if your child doesn't want to talk.
- Don't feel that you ought to have all the answers.
- Think about what is normal for your child and how you can introduce a bit of normality into their life, including friends and school.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.





Preparing your other children

This chapter offers advice about preparing and talking to your other children about their brother or sister who is likely to die. It also addresses the tricky issue of how they might react.

Trying to imagine what the whole experience has been like for your other children can be painful. The brothers and sisters of a child who has been ill can feel very left out. If they can explore their feelings, and have an opportunity to talk with someone about these feelings and about themselves, this can help enormously. If a great deal of your time is spent with your ill child, then make sure there is someone available for your other child or children, who they trust and can talk to. This will help your other children to feel important and part of what is going on. Even if most of your time is spent with your ill child, any separate time for your other children will be precious to them. It will also help them to feel valued and loved.

One 14 year old girl said “I was glad that mum talked to me, I felt I was going crazy, didn’t know if I was right, what I was thinking.” She sat down with her mother and they talked through what had happened to her sister. After their conversation, the girl felt all the family were able to talk more freely.

How can I help my other children to talk?

If your child’s brother or sister doesn’t want to talk to you, remember that it might not be the right time, in the right place or the right person. Not wanting to talk about difficult issues at any one time, should not stop people from talking about the subject altogether. They may want to talk about it later.

To try and get conversations going, you can try and find out what they know about what is happening to their brother or sister. Then you can ask them what they think is going to happen and finally, what they fear is going to happen. By taking these questions a step at a time, it can gradually bring out a conversation. Always be prepared to go at their pace and stop when you or they have had enough. You can always say, “We can talk about this later if you like”.

Memory or special boxes can be a good way of opening up conversations.

Doing activity workbooks such as “When someone has a very serious illness” or “Muddles, puddles and sunshine” (see page 60) or making scrapbooks, can help to open up conversations in a non threatening way.

"I made my own box about my brother. He knew I was doing it, and we'd laugh, 'cos he made one up about me as well, so we were both doing it. We talked about what things we enjoyed, what made us laugh and why things were special to us. After he died, it took me ages before I could look in my box. I saw that he had put in a tiny model of a rocket. That was special as he told me he'd go off on a rocket. That's how I'd know he was gone."

12 year old brother of a 10 year old boy

How will they react to hearing their brother or sister is going to die?

There are several ways in which children can react. Some children act as if they heard nothing at all. This can appear unfeeling but often this is a reaction to shock.

Other children may cry and some may get very angry. Others may have worked it out for themselves and are relieved to know for certain. This means that both can say goodbye. You can expect any of these reactions and their behaviour can change with lightning speed. They may be withdrawn, angry, aggressive, difficult, but quickly become clingy or grown up. It is important to remember a child shows feelings to different people at different times. Most children behave normally most

of the time, with periods of sadness, or clingy or angry behaviour.

One mother couldn't believe her son's reaction when he left the room and started to kick his football around. Maybe he hadn't heard what she'd said. It made her feel really angry. When she went out to check if he had heard and maybe to get cross, she saw his face. Yes, he was playing football, but he had tears streaming down his face. Then she realised that he was bound to react like that. Why was he suddenly going to change and go all soppy and talk about feelings when he'd never been like that before? Why shouldn't he have a cry when playing? It was his way of expressing his feelings. He didn't need words.

"Dad told me my sister was going to die soon. I thought no way, there is a mistake and after all, we had been told this was a curable cancer. It wasn't for her though. We did talk about it once. She told me she was going to give me all her photos and her laptop. I said I'd rather have her but she told me it didn't work like that. That was all we spoke about it, 'cos all she wanted to do was to hang out, listen to music like she always did. Actually that made it easier for both of us, even if we were pretending some of the time."

13 year old sister of a 14 year old girl



What should I expect?

There will be questions that you cannot answer at that time. Try to be as honest as you can and don't be afraid to say you don't know.

Be aware that your own feelings and beliefs will play a large part in how the child and the rest of the family will deal with the situation. There will be times when you will not be able to talk about this, and it is fine to be able to say that. Always try to say that you will talk about it at a specified time, so either of you can bring up the subject later.

Chapter in brief...

- Children will react in different ways.
- Brothers and sisters can feel left out.
- Find out what children know – this can open up a conversation.
- Memory boxes can be a useful way of getting children to talk.
- Children may want to talk at another time or with another person.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.



Children's ideas and understanding of death

In this chapter you will find information about how children make sense of, and understand, death and dying. Children's ideas change as they develop and according to previous experiences.

All children need to be helped to realise that death is part of life and that it can be frightening for adults as well as children. Children at different ages, have different understanding and beliefs about death. Your child may know more or less, depending on their age, maturity and experience. Children being treated at a hospital may well know other children who have died. They are likely to have more of an understanding of death than could be expected in most children of a similar age. It can seem confusing but children are capable of holding conflicting ideas at the same time, that at times they know they are dying, but will also talk about their hopes for the future. The sections below are only a rough guide to how children may understand death.

Pre-school children

A pre-school child may not necessarily understand the word death. When introducing the subject to a pre-school child, start by letting them tell you about death. Reply to any questions with very simple short explanations. When you have answered them, stop. Try to relate death

to things they can understand, such as the death of a pet, or finding a dead insect. They may not believe that death is final and sometimes think it is like sleep, and that you can wake up. At ages three and four, children often include death in their play and can get very confused about the difference between fantasy and reality.

"My three and a half year old son was always asking me, 'why do people die?', 'when will I die?',... lots of questions like that over and over again. I know he was at that age, but also his brother really was going to die. I told my little boy that people die when their bodies really don't work very well any more, that they are very, very ill, and that then it is the right time to die... That stopped him asking, and actually helped when my elder son did then die a few months later."

Mother of a 3½ year old brother of a 5 year old boy

At first, a pre-school child may seem to accept it but then expect the person to return. They ask lots of questions such as "Do dead people eat?" or "Can they watch TV?", "What happens when people die", "Why do people die?" Their understanding will be



linked to their experience and curiosity. They may have known other people who have died, possibly other children, and this can mean that they understand more about death than other children the same age.

At this age, it is most important for the child to feel safe. Try to keep to their normal routine. This, along with plenty of cuddles, will help them feel secure.

Short, simple explanations are best. Always try and give an answer to a question, even if you can't give the reply immediately.

Children aged five to nine

Children of this age group begin to understand more about the meaning of death. At six to seven, magic and myth are very important concepts. Death is often associated with ghosts and witches and can be a very scary idea, but they also quite like this dark side of death. They may fear that a dark scary monster could take them away. Children at this age also may start to talk about heaven, paradise or an afterlife.

Children at any age can also feel responsible in some way for the death of their brother or sister. Feeling that somehow, something that is happening is their fault is called 'magical thinking'. Children of this age often strongly feel this guilt and responsibility, and may need a lot of reassurance that it is not their fault. Children of eight to nine begin to sense that death is more final. They may feel responsible or relieved and may worry

about parents' reactions.

This age group generally cope best when they receive simple, honest and accurate information. They can be told that it was nothing they did or did not do that caused the death.

"I heard someone say that I wasn't going to get better. I knew that already, the chemo had gone on and on, and then suddenly it had stopped even though I was supposed to have the next block. I suppose that means I am going to die...well I know that I am going to heaven, to be a guardian angel. I don't really need my body any more."

7 year old girl

Children aged ten to twelve

Most children by this age realise that everyone dies. Death is often seen as frightening, gloomy and horrible, but fascinating. Death is final and not reversible. Children's thoughts can become abstract and spiritual, stretching their understanding of what is happening to them and within the world.

At this age, children cope best by establishing support systems with parents, friends and other family members. They can be given the opportunity to express their feelings, using conversation or other creative and artistic means.

One father sat down with his ten year old son and talked about how his friend had died during his bone marrow transplant. His son said "I'm not even going to get to transplant am I? I am going to die aren't I?" They talked about death, how the body stops working and that actually everybody dies but he may die quicker than everyone else.

"We had a long conversation about what may or may not happen. How many parents can say they've had that kind of conversation with their child? I feel privileged."

Father of a 10 year old boy

Teenagers

Teenagers are often concerned with their own identity and their position within their family and circle of friends. They may think about the deep issues of life and death. Teenagers are very aware of their own

body image and as death is involved with the destruction of life and body, it can feel particularly threatening. Expressions of emotion may be hard. Some teenagers will want to grieve openly and others will find it easier with friends, rather than with family. Helping teenagers cope is about trying to get the balance between support and respecting their space and identity, and will most often be a compromise on both sides.

"My 15 year old daughter was talking about existentialism.

Apparently they'd been doing it at school. She told me that she thought it meant everyone just went on and on, that life goes in a cycle. She wasn't sure where death fitted in. Life is just so immediate for her and her friends, even though she knows she has cancer and they can't cure her."

Father of a 15 year old girl

Chapter in brief...

- Children need to be helped to realise that death is part of life.
- Children's understanding of death will depend on their age and past experience.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.





The last few days of your child's life

This chapter offers suggestions about coping in the last few days of your child's life and how you might try and meet the needs of all your family. It also looks at feelings families have experienced about what happens at the end of life, and what has helped them and their child.

Many parents feel helpless and useless when their child is dying. They may feel there is nothing they can do. Perhaps they feel guilty that they sometimes feel exhausted with caring for their child. Most children find that having their parents with them is an immense comfort. It may be the most important thing you could do for your child. Your child may also need to have some time away from you and need their own space, and time with others. A respect for your child's wishes is very important, even if you feel rejected at times. Some children want to protect their family and friends. Others may distance themselves or take control of who should be there.

Listening to what your child says, and being aware of what they don't say, is very important. Try to honour your child's wishes and help them with unfinished business.

Where should my child die?

Most parents want to know where their child can die and how it will happen.

Where your child dies is very much up to you as a family and what you feel is best. You can always change your mind. Many children prefer to die at home. This offers familiar surroundings and the comfort of home. Family, friends, toys and pets can be close to hand. It may be easier for brothers and sisters to be present. If the brother or sister changes their mind, needs to be out of the room, or just wants to escape from it all for a while, you may want a relative or close friend to look after them. Doctors and nurses will visit and help.

"Once we had talked about the fact she was going to die, we (my daughter and I) sat down together and made a list of things she wanted to do, what she wanted me to do, what she wanted her friends to do. Even though it was probably the hardest thing we have ever done, I am so glad we had this time together. I could show how much I loved her, and really wanted to hear her feelings, even if it was unbearably difficult. I am proud of both of us, and will never forget those lists, and still have them now."

Mother of a 15 year old girl

Sometimes children need to go back to hospital or a hospice for a short time for symptom control. It is your choice if your child stays there or is taken back home to die. Events may not go as planned and your child may not die in your chosen place, or it may happen rather more quickly than expected. Experienced staff will help guide you at this time and ensure that your child's symptoms are well controlled.

When do we have to call someone?

If you think your child is about to die and you wish someone to be with you, you should be able to call your doctor or nurse to arrange this. You do not have to call your GP or funeral director straight away, particularly when you want some time on your own with your child and family. It is very helpful to talk about this with your doctor or nurse in advance so they know what your wishes are.

Who should be there at the end?

Many parents and brothers and sisters imagine that they will be there at the time when their child dies. For some, this is very comforting. However, it can be difficult for parents if they are not with their child when they die. Nurses, who have had much experience in this, say that often our loved ones just cannot slip away while people who care about them are around. Children sometimes die when a parent has left the room.

"My son seemed to hang on and on, even though everyone had told me days ago that he was only hours from death. When I popped out of the room to get something, he died. At first I felt so guilty that I was not in the room with him, but then when I thought about him, I think he was waiting for me to go, and that I didn't actually need to be with him at that moment. I think he was giving me a message that I could go on without him and that he could go on without me."

Mother of a 12 year old boy

Some children may be aware of their relatives' sadness and may be trying to protect them from it. One son told his mother, as he was slipping into a coma, to go and look after his sister. They had said their goodbyes earlier and his mother felt that he knew how upset she was going to be. She felt he was protecting her from pain.

Brothers and sisters who are included at this time, generally cope better in the months following the death of their brother or sister. However, if the child who is dying, or their brother or sister, has strong opinions about this, it is crucial to listen to them. Respecting their wishes allows them to feel more in control.



Respecting your child's wishes and privacy may also mean vetting visitors. You may want to appoint a third party to give out important information so you and your family can spend time together uninterrupted.

How can I make my child more comfortable?

As a parent, you know your child best and will have their likes and dislikes at your fingertips. You can make them feel comfortable by letting them watch what they want on television, listening to music, favourite stories or other activities. Just being able to do things together, or setting up things for them to do, can be liberating and of great comfort. Keeping your child occupied, interested and stimulated will give both of you something to focus on.

Many children stop eating and drinking towards the end, so don't expect your child to want, or need, food or drink at the very end. Helping to keep their mouth moist provides comfort and the opportunity for closeness. Offer ice chips and ice pops as they can help dry lips and mouths.

Physical contact can be soothing, particularly if it happens with favourite music. Massage or regular turning to reduce sore skin can be comforting. Cuddles for those who enjoy them can be the most important thing a parent can do, as it allows the family to be really close.

How will the end be?

We all have images conjured up by television

and films, which are probably not very accurate. Nobody can tell us for sure how the end will be, but often the moment of death is peaceful. The skin colour can become paler and breathing becomes shallower or uneven until it stops completely. The child is often unconscious or sometimes sedated or very sleepy. Sometimes he or she will wake from this state for just a few seconds. It is said that people can still hear and sense touch in an unconscious state, so it might feel right to talk to your child and stroke their hand. However, sometimes the death is not like this at all and this can be distressing for the family. Sometimes the child becomes twitchy or agitated before they die. This is a physical sign that they are close to death and not that they are distressed or upset. No two deaths are alike. Your doctor or nurse will be able to discuss what is likely to happen as your child nears death.

"She sort of just slowed down.... time seemed to just stand still..... then there was nothing and I suddenly realised I couldn't hear her breathing any more. I know it is so different for everyone but actually her dying in my arms quietly, was what we all wanted. I was cuddling her, her sister was brushing her hair, my husband was stroking her hand. We were all with her, touching her."

Mother of a 12 year old girl

What about children who die unexpectedly?

This can feel especially cruel if you had hoped your child would die in a certain place, and with certain people around. To feel unprepared can make the experience seem even more out of your control. This may make you feel helpless or hopeless, especially if you feel there is still unfinished business. For example, that goodbyes were not said or last messages were not conveyed. From the child's point of view, what is always most important is to know they were loved. Even if one last message re-confirming that was not said, the child would have known they were and always will be loved. It can be very difficult to accept when a child dies totally unexpectedly, such as when they were on active treatment, when families were not expecting this to happen.

What happens immediately after the death?

For some people time stands still. Remember that nothing has to be done in a hurry. Your child initially becomes pale, then cold, then becomes stiff and eventually relaxed again. You might wish to sit quietly with your child and talk to them or hold them in your arms. There are no rules and it is important that you do as you wish. Some well meaning people may believe it is better to call the undertaker quickly to help everyone cope better. This is up to you.

You do not even have to use undertakers. If you want, you can keep your child at home until the funeral. It is worth, however, taking advice from an undertaker, particularly in warm weather conditions.

You may wish to take photographs and perhaps a lock of your child's hair, or a hand or footprint. You may also want to wash your child and dress them in a favourite outfit. When your child's body is at the undertaker's everything can seem distant, but it may also be comforting to know your child is somewhere safe being looked after. One father carried his little daughter out into their garden after she had died, because she had played happily there when she had been well.

Spiritual questions: what really happens after a child dies?

No one can really say for certain, but many people believe that the spirit of the person flies free of their body. Some think the spirit goes to heaven forever and some believe that the spirit is eventually reincarnated into another body at a later date, sometimes within the same family. Even if you believe that death is not the end, you may still need to mourn the fact that you will miss your child in your lifetime.

Some parents believe that death is the end of everything. Even parents who have quite strong religious beliefs, sometimes feel the need of reassurance that their child is happy



somewhere else. It is certainly important to find what rings true for you, even if it differs widely from what you were taught to believe in. The death of your child can be a time of enormous growth spiritually. The spirit of a person may be what makes each one of us unique and special.

How will I feel after my child has died?

A wide range of feelings is normal at this point. These may range from disbelief, anger, extreme tiredness or uncontrollable tears, to a feeling of peace and almost relief that your child's suffering has ended. It can be a feeling of 'sweet sorrow'.

"I still feel guilty that I was relieved when she actually died and that she really was at peace. In the end, that was what I was really hoping for. After she died, she looked peaceful. In fact only then did I realise how uncomfortable she must have been, because her face sort of relaxed. That helped us all in some way; that my true girl was back."

Father of a 17 year old girl

Another parent felt nothing, even when she was ringing the undertaker. She supported family and friends, and felt as if she was talking about someone else, not

her own son. It wasn't until she saw the coffin that she felt something. This is a very natural reaction to the pain of losing someone you love very much.

"...All I could think was he was in there (in his coffin). But he couldn't be, he wasn't supposed to be in there. It all hit me then, I was like a jelly. I think I turned into some sort of madwoman for a bit. Actually, although it felt it was going to feel like that forever, it didn't. We did get through the rest of the month, the year. You know I can smile again now without feeling guilty. You wouldn't believe it, but it does change, believe me."

Mother of a 3 year old boy

Chapter in brief...

- Think about where you would like your child to die and who should be with them.
- Try to respect your child's wishes and those of brothers and sisters.
- Although you may wish to be with your child when they die, your child may be waiting for you to leave the room.
- Brothers and sisters who are included at this time may cope better in the following months.
- Try to encourage gentle pleasurable activities such as listening to favourite music.
- Physical contact can be soothing.
- Try not to worry if your child doesn't want to eat or drink.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.





What to do after your child has died

This chapter covers some of the practical details and tasks that need to be done after your child has died. This includes registering the death and choosing an undertaker. We also offer advice about contacting others, in particular, your child's school.

Registering the death

The death of your child must be registered within five days. If you feel this is too much for you to cope with, a relative or anyone who was present at the death can register the death for you. If you decide to do this, it may delay the paperwork that you will need for organising the funeral by a few days. This is because the necessary certificates will be posted rather than handed to you personally.

The death must be registered in the sub-district where it occurred. Register Offices are open Monday to Friday. You will need to contact your local office to check their opening times. Many offices operate an appointment system so you don't have to wait.

What will I need to register the death?

- A death certificate which states the cause of death and is signed by a doctor. If a post mortem is needed, there can be a slight delay in issuing the death certificate.
- Your child's full name, home address, date and place of birth.
- The parents' full names, home address(es) and occupations.

Don't worry if you do not have all of these with you as this will not delay the registration of death, or the funeral arrangements. Neither do you need to take your child benefit book or child's medical card. The registrar will give you a special certificate for the DSS. This needs to be completed and returned with the books to the appropriate office.

Choosing an undertaker

If possible, take some time to choose an undertaker sympathetic to your needs. The local religious advisor or the hospital can give names of undertakers with experience of children's death and funerals. Watching your child's body being taken to the undertaker's chapel of rest can be a painful experience. Going to see your child there can also be very difficult, although it can be a time when the whole family can begin to grasp what has happened. It can also be a time to talk to your child and touch him or her, or to pray or carry out any religious practices that are important to you. Children in Focus (see page 58) are an organisation who will advise on local funeral directors who have reduced or minimal costs for children's funerals.

You may choose to keep your child's body at home until the funeral. If you do this, it may be useful to contact an undertaker for advice. You may choose to have your child's body to stay at the undertakers until the night before the funeral, when they can be brought home. All these decisions are a matter of personal choice.

Some undertakers put make-up on children, and if you do not want this, then say so. Chapels vary and there may be changes in how your child looks, as your child would probably look different with make up on. You may prefer to call your child's coffin a casket, which means a place for treasure. Some families put letters or favourite toys and precious mementos in the coffin.

Contacting the school

After your child has died, you will need to let the school know. If you wish, someone could do this on your behalf. The school may want to have a special assembly. They may also feel they would like to make a more permanent memorial to your child in the months that follow. Some schools have benches or seats with plaques, or special trees planted.

Sometimes, schools want to hold a service. You may want to get your wishes as a family across, if you feel this is too soon or at a time that is too difficult for you. If you already have a liaison person at the school, they will be a useful contact.

This is particularly important for schools where there may be a brother or sister still attending. No one wants to make the situation more difficult than it is already.

Your child's friends may wish to read poems, play music or sing songs at the funeral or thanksgiving service. You and your family can decide what feels right at the time.

"My son's school was fabulous. The whole of his tutor group came to the funeral with their tutor and some even read out poems. It was very touching and I was full of respect for all his friends who spoke so movingly about him. It was a real tribute to the quality of their friendship."

Father of a 16 year old boy

What about my child's friends?

Friends are such an important part of children's lives. Often they wish to help out with the funeral, or to visit and share memories. Many friends of children who have died, remain in contact for years. This can be a sign of respect and also an acknowledgment that your child, their friend, was and still is an important part of their life.

Who else should I contact?

It is useful to write to tell everyone who may send out appointments or who may



still have your child's name on a list. It can be upsetting to receive appointments that are no longer needed. It may be easier to nominate one person to do the ringing around on your behalf. The list probably should include the following people:

- school
- hospitals or clinics involved in your child's care
- your GP (especially if they have not had much contact over the last few weeks/months)
- dentist
- health visitor
- any clubs your child attended or was on the waiting list for.

Chapter in brief...

- You need to register the death within five days.
- You may choose to keep your child at home until the funeral.
- Think about who you will need to tell after your child has died.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.



The funeral and celebration or memorial service

This chapter offers suggestions and ideas about different funeral services. We look at what other families have done or found helpful or comforting.

Making decisions at this time can seem very difficult. You may have already had time to think about, or plan, the funeral. It is important to do what feels right for you and your family. The funeral can be a very moving occasion for you and everyone who knew your child. You may want a religious service or you may want a private service and a thanksgiving for the life of your child later. Almost anything is possible. A large gathering of friends and relatives can be very supportive and make you realise that your child's life touched a great many people.

The funeral can be a day to remember although you may not think this at the time. It can be a comfort to feel you gave people the opportunity to say goodbye to your child. You may wish to have the service recorded and photographs taken, which can be appreciated at a later date. You may also like to have a visitors' book for people to sign at the door as they come in, or go out, or a book of remembrance for people to write something about your child. To avoid a queue of people waiting to sign a book, one family had little cards put out in the church for people to fill in, which they placed in a special basket when they left the church. As

this will be a very busy and difficult day, it may be useful for you in the future to know who was there at the funeral.

"My daughter's best friend made these gorgeous glittery cards, and we put them on all the seats in the church along with a silver pen. She had written 'Memories about Amy' on the top of the card. We asked the vicar to introduce them and to ask friends and family to fill them in and leave them in the special box at the exit. They are beautiful, and made my daughter come alive again through thoughts of others, and to realise that she was special to others as well as to us."

Mother of a 15 year old girl

A burial or a cremation?

For some families, this can be a difficult choice. For others, the decision has already been made for cultural reasons. Remember that brothers and sisters can have strong feelings about the body being burnt or buried. This can also be too painful for adults to contemplate. Your child may also have had strong feelings about it. One little boy was adamant that he did not want to be cremated. The thought of burning was



just too frightening for him. He was able to say that he would prefer to be near a tree because he liked trees. His family chose a woodland cemetery which was a lovely place to visit, and where there was no need for a headstone, just a special tree. A grave or place where ashes are scattered or buried can be very meaningful. All choices made at this time should be made by the family, without pressure from anyone else.

Where should the service take place and who should lead it?

For some families, the funeral will automatically be in a church or a place of worship. You may prefer an undertaker's chapel or a cemetery chapel or at a graveside. Crematoriums can be busy places, so you may wish to consider booking two slots to avoid contact with mourners from other funerals. Alternatively, you could have the service at home or in a special chosen place. The service can be religious, non-religious or humanitarian. Clergy are experienced and are often very sympathetic towards a non-religious approach. Friends and relatives can also speak at the service and this can really help make the day personal to your child. There are no rules and, the more you are involved in planning the service, the more memorable it is likely to be for you. You may be able to take in large pictures of your child, or to decorate the venue in such a way that it reflects your child's personality and wishes. Sometimes families

invite their children's friends to take part in the service, but for some friends, whilst they know it is an honour, they just can't do it. If this is the case try not to feel disappointed if they can't take part. Sometimes they can play another part by choosing some music or letting somebody else read something for them.

Your child may have planned their own service and even a gathering afterwards, before they died to ensure that it is not all doom and gloom. There is a great satisfaction in knowing that you have honoured your child's wishes.

What about service sheets?

Service sheets can be a way of recording the service and can be simple or elaborate. They can be professionally printed or hand written and photocopied. They might include a few words, a photograph, or a picture drawn by your child and contributions from their friends. Many friends, staff from the hospital or hospice involved with your child and family members, treasure these sheets as a tribute and memento of your child.

Should there be flowers or donations to a charity?

This is a matter of personal choice. Most families want some flowers on their child's coffin. However, sending money to a charity connected to the child can be a lasting tribute.

Should brothers and sisters be present?

Children usually want to be included in the funeral of their brother or sister. This may be a painful experience but they may be much more frightened about what is happening if they are not allowed to be there. Explain to them beforehand what is likely to happen and give them the choice of whether or not to go. Sometimes brothers or sisters just come to part of the service, rather than all of it. You probably need to have a friend or relative on standby, to take the child somewhere else if they feel they can't stay.

How should I dress for the funeral?

It is important to be comfortable. One mother knew her little daughter had admired her yellow tights before she had died and so she wore them for the funeral. Some families request that nobody wears black. Most funeral directors will also dress in lighter colours if this is requested. It is really helpful if you can be very clear to all those who are attending the funeral what you want them to wear or not to wear, so they know what your wishes are and there are no misunderstandings.

How am I likely to feel at the funeral?

Feelings can range from unbearable sadness to numbness or even a sense of relief. The funeral may provide comfort in time to come, when you may remember it as a special memorial to your child.

You may feel like throwing yourself into furious activity and pretend to be cheerful and bright as if nothing has happened. This is a common reaction and it does not mean you are not grieving. Sometimes at funerals it may feel as if the family of the child who has died is comforting the mourners. This can feel strange and challenging, but often happens.

"I seemed to be on automatic pilot, I even managed to talk about my wonderful three year old. I can't believe I did that now. I can hardly remember the day at all, even though everyone tells me we were magnificent. Were we? I really don't know, but at least the funeral is over now. What next though?"

Mother of a 3 year old girl

What about the gathering after the funeral?

You and your family may wish to be alone after your child's funeral or you may like relatives and close friends to be around. One little boy, who had always enjoyed family and friends' get togethers, asked his mother before he died if they would have a party for him after his funeral. A gathering can sometimes be a way of bringing together those who have been involved in your child's life. You may choose to hold this in a hotel, a pub or at home.



How can I thank those who came or sent cards?

You are likely to be overwhelmed with lovely important messages and cards from those who knew your child. It feels so important to be able to reply to everyone, but also it can be very difficult to face writing a personal reply to every card or message. Some families have sent out a simple 'thank you' (for your kind and lovely thoughts) card. Often the families have designed these themselves; some have put in a photo of their child or a special picture. This can mean you do not need to write personally in every card, but that you are able to show your friends and family that you appreciate their thoughts.

Can I have any help with funeral costs?

A number of undertakers operate a policy of not charging for their professional services when the deceased is a child (up to 16 years). In particular, a large network of affiliated funeral directors is part of a special project

called Children in Focus (see page 58 for contact details). As well as making minimal or no charge for their professional services, they have also been looking at ways of making funerals more acceptable for children and families. This includes: different styles of coffins, special memory boxes for children to store treasures to remind them of their brother or sister who has died, and special chapels of rest.

Families who are receiving certain benefits may be eligible for a payment from the Social Fund to help with funeral costs. These benefits are currently:

- Income Support
- Income Based Jobseekers Allowance
- Working tax Credit where a disabled worker is included in the assessment
- Child tax Credit at a rate higher than the family element
- Housing Benefit
- Council tax Credit.

Chapter in brief...

- Consider the opinions of brothers and sisters when planning the funeral.
- The service doesn't have to be religious.
- You will probably want to make the funeral and the funeral setting personal to your child and to your family. For example, using photographs, readings, visitors' book or cards.
- You may be entitled to some help with funeral costs.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.



How we grieve

In this chapter you will find information about how children and adults grieve. Knowing what to expect, and what others have experienced, may help you to see a way forward when grieving for your child. Children may seem to understand about death one minute, and then seem to change their mind the next.

Grief is a normal part of life and part of the healing process for all losses. It is usually thought of as a feeling of sadness and unhappiness about the loss of someone or something important. When a child dies, you and your family may lose the dreams and hopes you had for their and your future. This can be very hard to deal with, realising that your hopes for the future can't be as you had wished.

Children's grief

Most children will grieve openly at times but will behave normally the rest of the time. Children have fleeting emotions, which change very quickly and which can be confusing for parents to watch. Children's grief has been likened to a child jumping in and out of puddles. The child may not really believe a death has occurred and hope that doing something different may just bring the dead person back. Children's reactions will change according to their understanding, age and how they felt about the person

who has died. They can be expected to have a wide range of feelings. Some children take months or even years before they want to talk about their brother or sister, while others will talk about them continually. You cannot force a child to talk about something if they are not yet ready. It is important, if you can, to talk about your dead child and to bring them into the conversation. Sometimes the child will not say anything about their dead brother or sister. The parents may need to accept that it just may not be the right time, person, or place. The child may need permission to talk about their brother or sister and may feel frightened that talking about them will upset you. They need to know that even if you get upset, they can still talk to you.

How children of different ages grieve:

Pre school children:

Pre-school children may have a heightened sense of anxiety when separating from those close to them and become very clingy. They may also become withdrawn at times. Pre-school children can be protected by their lack of understanding and inability to understand the long term implications. Making them feel secure and maintaining a sense of normal routines may help this age group to settle. There may be some signs of regressed behaviour. For example, starting to bed wet again, tantrums starting again. These are all signs they want a little more



attention. Young children, will almost always need more detailed explanations about death as they grow older. They are likely to grieve differently as they get older, and as they become more able to understand what has happened.

School age children:

School age children generally have a wider range of coping strategies, from normal behaviour to more adult expressions of grief. They may also act like a much younger child. Often they display fluctuating behaviour. They may appear normal, withdrawn, sad or angry. School age children will need time and space to be able to talk about what has happened, and to know that if they want to talk they can. It can take a long time for some children to grieve openly, and some choose to always do it in private. It is important to let them know that they can talk when they want to, or to be able to offer to find someone else for them to talk to. If you feel a professional or someone outside the family could help, see the useful support section at the end of the booklet.

Teenagers:

Bereaved teenagers often show changed behaviour. They may act out of character or behave unexpectedly in a situation. The death of someone they were close to often results in more conflict with parents and increased rebellious or difficult behaviour, or conversely spending more time at home. They can become protective of their family and often become more judgemental about

themselves. If there is someone who the teenager feels comfortable talking with, then encouraging them to talk with them or with you may help to give the teenager permission to be able to grieve or express their feelings.

It is also important to realise that, even if a child initially did not grieve, they may ask questions in the future. The grief may emerge at a later date, probably when you are least expecting it.

"My daughter was four when her brother died, and seemed to accept it, although she was always searching for him, and asking where he had gone. Life did settle, but suddenly her behaviour started to change... Now she is 12, and suddenly acting out of character, stealing money, getting aggressive. At first I thought it was just teenage years but then she began to talk more and more about her brother. I realised we hardly talked about him any more and had hardly any pictures of him up. She was starting to grieve, I can see that now."

Mother of a 12 year old girl

Why do children seem to accept one minute then not the next?

Children can fluctuate widely in their views of the reality of death. They usually

have a basic understanding that someone might die. However, this may alternate with disbelief and this can be confusing for adults to understand. Many factors can influence how and whether a child will talk about the death. These factors include:

- Who the child is talking to (may not want to upset or may not trust someone)
- The place (may not be the right place to talk about it)
- How the person is talking to them (are they listening to the child and respecting them?)
- The child's age and ability to express themselves
- Worries about death or pain
- Personal and family communication styles
- Cultural views about death
- Denial that death can happen
- Guilt that the child thought it may be their fault in some way.

Fluctuating views about death are normal for most children. It allows children to have the opportunity of finding out what other people are saying or thinking. It also allows the child to be in control over what they choose to talk about and with whom they talk.

Adults' grief

The feelings of grief described below do

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not necessarily happen in any particular order. They may all happen at the same time or disappear and re-appear at a later date. Therefore, grief is shown by different people in many different ways.

Numbness: a lack of any feeling, which most often happens just after the death and acts as protection for the bereaved.

Shock: your world is destroyed because you have lost a very important person. Your life may feel as if it has lost all meaning.

Anger: real fury that this has happened. This can be the most confusing feeling. This sometimes may be directed at people who were not responsible for what has happened.

Despair: once it has been realised that no amount of searching or longing will bring back your child.

Searching: yearning for your dead child, what they might have done, and the loss of your dreams for them.

Denial: behaving as if the dead person is still there, a strong feeling that this has not really happened.

Anxiety: feeling insecure, not knowing where you belong any more.

Guilt and self reproach: often mixed with anxiety, and often is a feeling that as a parent you should have been able to stop this from happening.



Growing awareness: savage feelings that burst into your mind, over which you have little control. These include guilt, sadness, loneliness and anger, and the beginning of acceptance that this really has happened.

A feeling of madness: intense feelings of loss of control.

Loss, grief and death are part of life. It is often said that it can be easier if shared but this is not always possible or true. People grieve in different ways at different times. How people react is always personal and family members rarely grieve in the same way.

It has been said that when a person who you loved very much dies, the relationship and bonds between you continue and a new type of relationship begins with that person, although this takes time to build.

"When my son first died, there was just this empty hole, a gaping chasm where he should have been. Then slowly I began to imagine what he would have said, and oddly enough, I can even imagine how his advice would be different now, as he would have been older. It's weird, but our relationship changes. He'll always be my clever irresistible, son. But I can see the world through his eyes, and have even taken on his motto, 'carpe diem' (seize the moment) and I do."

Mother of a 17 year old boy

Chapter in brief...

- Children's reactions will change according to their understanding, age and how they felt about the person who has died.
- The reactions of children can change quickly.
- There are wide variations in how adults grieve, making it difficult to share with those close to you.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.



The first few weeks and months after your child's death

In this chapter we look at how families may feel in the first few weeks and months after a child has died. We look at worries and fears that are shared by many families and how to recognise when your other children may need extra help with coping.

Life usually feels unreal. One Mother said "How can people still be going to work, children going to school, everyone carrying on as normal when my child has died?" You may feel numb, in shock, or in complete denial about what has happened. The pain at this time can be very raw. You may find it difficult to organise ordinary everyday things. It is hard to concentrate on anything and you may not be able to remember things. You might feel as if you are going crazy. You are not going mad. All these feelings are normal for a person who is grieving. If they persist or you are worried about yourself or any member of your family, see your GP or talk to staff from the hospital

How long will we grieve?

Most parents never get over the death of their child completely and would not wish to do so. The pain does ease and living with the death of your child will become part of your life.

One mother of a two and a half year old boy thinks about him every day and still talks to him. She looks for things she can enjoy that he had loved and, in this way, gains a little pleasure. Her whole life has changed.

"I really felt like a mad woman, nothing felt normal, everything felt exaggerated and raw. Thoughts just rushed around my head, chasing around and around, all about my daughter. I couldn't think about anyone else even my older son... I went to speak to a bereavement counsellor. I wasn't going mad, I was grieving so much it physically hurt. That has changed now and I can think straight, but I needed to do that. Sometimes you need a bit of madness to recognise normality."
Mother of a 3 year old daughter

The Native Americans have a custom that when a loved one dies they go out into the forest and put an axe into a tree making a very large cut. They visit this tree whenever they feel the need to be very sad and think about the person who has died. Slowly the wound in the tree heals but there is a scar in the trunk forever and perhaps this is a little how it is when a child dies.



How will other people react to me?

Other people cannot necessarily see how you are feeling. They may not want to mention your child, in case it reminds or upsets you. You may feel angry when others are not as sensitive to your needs as you feel they could be. Other people may need you to tell them whether or not they should mention your child.

"I ended up telling a friend of mine to go out and tell everyone. To say that I needed to still talk about my little girl, to never mention her seemed cruel as if she had been forgotten. She did have a life, however short. She did mean something, and to talk and mention her helps. I don't care if it makes them feel uncomfortable, I am her mum, and I need to talk about her. I know it sounds pushy, but what about me, my feelings?"

Mother of a 4 year old girl

Worries and fears

You may be frightened that you will forget what your child looked like. Or you may be haunted by the way he or she looked when they were so ill or just after they died. Memories change and in time you will remember more of the good images than the difficult ones. It is probably not wise

to make any big changes in the early days. If seeing their belongings really upsets you, they can be packed up and put away, out of sight. You can always choose some of them to have around later on.

You may feel guilty about what you wish you had done or said. There may never have been enough time to say goodbye. You may wish you had treated your child differently in some way. Or that their illness was your fault in some way? It may help to discuss these feelings openly with a trusted friend or professional.

"At first I felt I was haunted by seeing her in her coffin..... Now a year on, I can see other pictures of her in my mind. I can remember her laughing, skipping, singing and doing the normal things everyone takes for granted. Those are the memories I cherish and they have come back."

Mother of a 7 year old girl

How will I fill my time?

Many parents feel they will have nothing to do, as so much time was spent looking after their ill child. So much energy, thought and worry was concentrated on getting through each day. What you do with your time now will initially feel very strange as your routine will change. You suddenly have

the time to look after other people or to spend time on yourself. It can be difficult switching your focus in life from one family member to others. Roles within the family may have changed and life will be different. Slowly your family will adapt to meet everybody's needs.

"My sister died. After months of being the last one anyone thought about, suddenly I was the centre of attention. Every little thing I did was looked at; I felt as if I was under a microscope. I couldn't switch from being the one left out to being the special one. It was crazy. I had to tell mum and dad to back off and life is now more easy going."

14 year old sister of a 13 year old girl

What else can I do to cope?

Some families feel they coped by trying to raise money or awareness about the illness their child had. Fundraising or joining a charity helps some parents and families feel they are giving something back. This is very individual and if you do this, it is important to recognise that you can stop being involved with the charity at any time.

Family relationships

Tensions within the family are almost inevitable. Rarely do two people grieve in

the same way at the same time. Everyone can be in such intense pain that they cannot help anyone else.

"After my brother died, suddenly my parents stopped me going out with my friends, going on the bus on my own. They even drove me to school. It drove me mad, I thought they were punishing me. I think actually they were just trying to protect me. They didn't want to lose another child. It didn't work though as I just went out anyway. Now they have realised they can trust me. It was a tough lesson. It didn't help at the time, as we should have been close but the petty rules were crazy. At last they see my point of view, although it took some time."

17 year old sister of a 14 year old brother

The idea that such a traumatic experience automatically builds up a wonderful bond between you is, unfortunately, not always true. It can be upsetting when friends assume this. Allowing each other to grieve in the way in which they choose can be very difficult. If a couple can accept the other's differences it can build a respect and a special relationship, which might not have otherwise developed. This takes time.



It is sometimes difficult to feel any emotions for surviving children. It may feel unfair that they are still alive and that they will never match up to your dead child. Fortunately, these feelings usually pass.

Sometimes parents will have an overpowering desire to protect their surviving children and not allow them any freedom. This is especially difficult for teenagers. It can also be very difficult to maintain the same relationships you had with your other children. Being close to a child is a reminder of what you have lost. Some parents may find themselves feeling detached from their other children. These difficult reactions change over time, as your family adjusts to living together again.

How can I tell if my other children are struggling?

Many parents ask “What are the danger signs that my child may be struggling?” Several weeks of problems are normal, but if you are really worried, or the changes carry on for a few months, then it may be useful to contact the hospital where your child was treated or your GP for advice and referral. It may be useful to ask yourself:

- Has your child’s behaviour changed? Even if they deny it, it is a sign that they are grieving, and can be a non-verbal way for them to signal that they are struggling. Think about who they can open up to, and try not to feel rejected if it is not you. This may be

because they are protecting you and because you too are suffering.

- Is your child having problems with sleeping? Has their appetite changed? These are all normal responses to upsetting events, and should improve over time.
- Does your child have bad dreams or nightmares? This is a common way to show distress. Talking about the dreams can be a way of opening up.
- Is your child acting as if nothing has happened? A lot of children act normally for most of the time. This does not mean they do not care or do not understand. They are acting normally, just having brief periods when they are upset. They could also be talking to someone else, for example, their pets, teachers or friends and be trying to act normally for you.
- Has your child developed new fears? This may show that your child is struggling.
- Does your child have developmental problems? A child may stop doing things they could do before. They may start to wet the bed or fall behind at school.
- Does your child have problems with holding onto relationships? If they start falling out with friends or boy or girlfriends, this may be a sign

that they are feeling unsure about themselves, and just feel very different to everyone else.

If your child has any problems which persist for a few months, or is becoming increasingly difficult to deal with at home, and is acting out of character, it is a sign they probably need to talk. This could be to you or a professional.

Bad days and good days

Some days will be worse than others. Grief tends to come in floods when everything seems unbearable. On other days, the pain eases and believing in the future seems just a bit more possible. It is usually better to allow yourself these bad days. They will get fewer as the months go by. Writing a journal or diary about your feelings might be helpful and this could be in the form of a letter to your dead child. It is important to look after yourself and others in the family, although you may not feel like doing so. Try to eat properly and get enough rest. Good feelings and times will gradually emerge. It does not mean you do not care or are not thinking about your child. You should not feel guilty; they are all part of learning to live again.

Returning to work

Some parents feel the need to return to work immediately, while others just cannot imagine how they will cope with a normal world. Unfortunately, economics sometimes

make a return to work as soon as possible essential. If you find yourself in this position, explain to your employer what has happened and whether you are happy for your colleagues to know. This could be done in writing if you preferred. Most employers will be very understanding.

How will people treat me at work?

Reactions are likely to be very varied. Some people may try to ignore the fact that your child has died and carry on as before.

"I have been amazed at the different reactions from people. I have discovered some true friends and been astonished at the lack of any overt kindness or even casual conversation from people I thought were my friends. I know it may be because they are uncomfortable but I have lost my son. If I can talk about him, why can't they talk to me? I think it is easier not to make a big deal about it and not to let it affect you. If they can't comfort you now, you don't need them. Friendship is a two way relationship. I feel this even stronger now than before."

Mother of a 12 year old son

Others will try to be friendly, but will be worried that they might say the wrong thing. One mother returning to her teaching



job after the death of her son was amazed by the reaction of a colleague. She had considered her a very understanding person, who then completely ignored her on her first day back and actually avoided making any contact.

As the weeks and months and years go by, your loss may be forgotten by others and you are considered back to normal. Difficulty with concentration and thinking clearly can continue for a long time. Sometimes it is necessary to remind those around you that life without your child will remain difficult for a long time, and to tell them what they can do to help.

Chapter in brief...

- After your child dies, everything may seem unreal. You may feel you are going mad.
- You may never stop grieving but this will become part of your life.
- You may have to return to work sooner than you like.
- You may lose the support of those you felt were good friends and be surprised by the support of others.
- You may forget what your child looked like.
- You may wish you had said or done things differently, but the most important thing is that your child knew they were loved.
- Your life will take on a new routine.
- You may feel overprotective to your other children.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.



The future and special occasions

In this chapter we consider what happens when you face birthdays, other festivals and anniversaries of the diagnosis and when your child died. We suggest what has been found to be helpful by other families, what they have done to mark special occasions and how to think about all the different members of the family.

The future may feel dismal and hopeless at first, but slowly life can get better. Feelings of loneliness and missing your child will probably last forever. Allow yourself those feelings. No one can tell you how long you will grieve for your child. The death of your son or daughter will have changed you, and probably your outlook on life, forever. It is important, however, to still remember the needs of your other children.

Sometimes the anticipation of special days is worse than the actual day. Family gatherings can be very painful and there can seem little point in making things special. Special occasions can also trigger memories and sad feelings. For example, family weddings or the birth of another baby when your child is no longer here makes it difficult to share their joy.

Christmas and other religious festivals

Festivals are supposed to be family times when everyone is together. Parents and brothers and sisters can feel desperately

lonely and isolated. All the tinsel and glitter, children's nativity plays and carols can seem unbearable. The build up for festivals can go on for such a long time that the pain of the festivities can seem unrelenting.

"It was very hard to talk to my mum and dad. They were always close to tears, or pretending to be jolly when I was around. Did they think I was stupid? Of course I knew they were missing him, but then so was I. Eventually I showed them a story I had written about being in the same room but being invisible. They realised what I was saying, and we are more honest now. It helps."

10 year old sister of a 7 year old brother

Some families buy presents for their child, knowing this is unrealistic, but find that it eases their feelings. Presents could be given to other children in memory of your child or a donation made to a relevant charity instead.

This can be a very difficult time for brothers and sisters too. A surviving only child suddenly feels that everyone else has brothers and sisters. They may also be angry that mum and dad seem so depressed. Children can make hurtful comments



without realising it. It can be difficult for parents to understand that their surviving child or children are working out their pain in their own unique way. Young children in particular often find comfort in traditions continuing in the same way as before their brother or sister died.

There are no rules which say you must have decorations. You may decide not to have any at all or just a few. Unpacking decorations can be unbearably sad as you recall happy memories. This is especially so in the first few years. One family had just a Christmas tree the first year after their only child had died. They decorated it in his favourite colour which was blue and they asked any friend or relation who knew him to put a small blue decoration on the tree. The finished result was very special.

What can help?

Some families decide to break with tradition completely and go away for Christmas or other religious festivals. Visiting your child's grave and putting some special flowers on it may help. Brothers and sisters could let off helium balloons with messages on them. It can be soothing to watch a balloon floating up into the sky. One family put a little Christmas tree on their daughter's grave and on Christmas Eve decorated it with waterproof ornaments and tinsel. They also hang threaded peanuts in shells on the branches as treats for the birds.

At festive mealtimes perhaps everyone could briefly stop and raise a glass in

remembrance. Tears are inevitable, but can be helpful. There are no rules which say you must be happy.

"The first year we went away.... my daughter didn't want to be an 'only child'. We couldn't bear all the happy Christmas cards. We had a miserable time. This year we stayed at home and it felt much better. There was no way our daughter who died would have missed out on Christmas, so why should we?"
Father of an 8 year old daughter

Christmas and greeting cards

Some families decide not to send cards in the first few years. Others may send simple ones as a way of keeping in touch with friends and relations who are important to them. Knowing what to write on the card is always difficult. Leaving your child's name off seems wrong, but somehow including it does not seem quite right either. Perhaps just writing 'From the Jones Family' or 'from us all' might be the answer. It might feel right to add a little gold star or a rubber stamp of something your child was very fond of, for example cats, dogs or other animals. One family has cards made from drawings their daughter had done before her death. They always add her name and dates at the bottom.

Cards from some people can be unintentionally hurtful. Somehow the words 'Have a very Merry Christmas and Happy New Year' do feel inappropriate to say the least and can make you feel extremely angry. How could people be so insensitive? However, it can be helpful to remember that these friends do want the best for you and are also feeling inadequate in this situation. Messages and flowers for your child's grave from friends and relations can be a real support. It means so much that others are also remembering your child at this time.

New Year

Everyone is celebrating and quite often, as bereaved parents, that is the very last thing you wish to do. In fact there is sometimes a very strong desire to hold back the years.

Birthdays

For some parents their child's birthday will be less difficult than the anniversary of their child's death. You may remember the joy of the new arrival but also feel sad, especially in the first few years. Again, you may have a wish to hold back the years. Some parents will want the time to go quicker, nearer to their own death. They may also try to imagine their child another year older. What would they look like, or be doing? These milestones go on forever. Anniversaries are always a time of painful reminders of loss. You may find rituals help or you may prefer to ignore the day. One

family always goes to the restaurant which their son liked best.

Sometimes giving brothers and sisters small gifts or having a special cake may feel right. Balloons could be let off with messages or candles lit as a symbol of remembrance. These can all help to make the day special in some way.

The anniversary of the death

This is a particularly difficult day for most families. The anticipation can be even more difficult as there may be painful memories of the time before your child's death. Flashbacks are almost bound to occur at the most unexpected times and are perhaps a necessary part of grieving. Music which was popular, the kind of weather conditions, even advertisements on the television can trigger unhappy memories. In order to remember the happier times, it is often necessary to go over, again and again the sad times. It can be important to recognise that the happy memories will come back.

Knowing how to spend the anniversary may be difficult. Special flowers and messages left on your child's grave and lighting candles may help to ease the pain a little. A service with close friends and family around the grave or where the ashes are scattered, may feel right. For families who do not have any particular religious convictions, gathering around the grave and talking about their child, or holding an alternative ceremony may be an option. Tears may flow, but this



may help to ease the pain. Some families choose to ignore the day or to be alone with their sadness. Whatever feels right is what is right for you.

There are so many dates which can trigger memories. The day of diagnosis is usually especially significant, as is perhaps an operation day or the start of treatment. Some memories will be sad but as the years go on, more will be happy. One family made their child's bedroom into a sitting room where all the family gather at special times. As one mother said, almost everyday is an anniversary of some sort for families who have had children who have died.

Chapter in brief...

- Anticipation of a special day can be worse than the actual special day itself.
- You may decide to break with family tradition and do something completely different.
- Sometimes traditions can help you cope.
- Greetings cards may be hard to write. You may choose not to send them or to mention your child who has died in a different way.
- You may find special ways for your family to remember special anniversaries.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.



Two to three years on and the future

In this chapter we look at life a few years after your child has died.

Most parents say that they still miss their child very badly but somehow the pain is not so raw. There will be situations, anniversaries and specific things which will continue to remind you. These may bring on feelings of sorrow as dreadful as they ever were, but they will probably pass more quickly. Some find that minor problems in their lives will spark another spell of feeling unbearably sad about their child. If this continues and does not pass quickly, then it may be helpful to ask your GP for advice.

Families worry that they will forget things about their child. It is comforting to know that these memories and images usually return even if they appear to have been forgotten. Photographs and your child's special belongings can help to bring out memories.

“How many children do you have?”

This is often a difficult question to answer. One mother who was on holiday a year after her teenage son had died, was asked by a kindly woman while sunbathing, “Is she your only one?” pointing to the mother's daughter who was splashing about in the water. The mother who was unwilling to spoil the relaxed, easy atmosphere replied “Yes”. She immediately felt dreadful, as if she had let her son down. She had to take

herself away so she could cry in peace, without further explanation.

Perhaps the best reply is simply “I have one daughter and my son died” quickly moving on to another subject, so that the enquirer does not have to be embarrassed. One mother replied “I have three children, and my daughter lives in heaven.”

“If someone asks me how many children I have, I say, ‘I have a wonderful four year old, who had an incredible sister who died last year’. I then carry on talking normally. I find if I carry on talking, it stops the other person from having to sympathise. I don't need any more sympathy but I do want them to know that I do have two children even if one is no longer here with us.”

Mother of a 4 year old girl, and a 2 year old girl who died

Each family will think of their own solution to the problem. Some are satisfied to only name their living children. One father referred to his daughter who had died as forever aged 6, for many parents their child remains in their memory as staying the same age as when they died, even though years pass.



What about brothers and sisters?

Many children are only now able to start to grieve and talk about their brother or sister openly. When brothers and sisters face other major life changes, such as changing schools or going to college, they leave behind friends, who knew their brother or sister. They now face new relationships which will be different. Brothers and sisters will also face how to talk about their family, and how to explain what has happened. For some, it is easy to talk about their brother or sister who has died, but for others this is never talked about. It can even be a relief that new friends will not necessarily have to face the grief and suffering that they had to. If they choose not to talk about their brother or sister who died, this does not mean that all is forgotten, or that they do not care. This is more to do with facing up to choices, and making decisions to keep certain things private with some people and public with others.

What about friends and other family members?

Probably only the very closest of friends or family will appreciate that your loss is still very much present. You may find you are upset and angry when people say things like “Oh do you still feel like that?” or “It’s about time you moved on from all of that.” These remarks may seem callous but they are usually made with the best intentions. It is also very easy to feel bitter about what

has happened and to resent other families whose children are all still living. Many families can feel jealous when they meet others where a child has survived illness and question why their child did not survive.

“I have to keep reminding myself that life did not stop when my daughter died. It did for us but not for others. They go to work, go to school, and live a life, whereas we live a strange, half-remembering, half-longing type of life. It is beginning to change. We still want everyone to remember we had a daughter, that she was special and will still be included in everything we do. She is too important to forget.”

Parents of a 17 year old daughter

What does ‘moving on’ mean?

This can mean different things to different people. Most families never completely ‘move on’ in the true sense of the words. However, their sorrow will intrude less and less into everyday life. The sorrow may also become more manageable, occurring for shorter periods, rather than being all consuming.

What about having other children?

Some families plan another child after the death of their child. It is not about replacing your dead child but about planning for the

future. It is acknowledging what you may want as a family to help you all cope. Some families feel very guilty if they have another baby, as if they were somehow letting their dead child down. In this case it is very important to be able to talk about this openly. To talk about how having another child will never take away or replace the special relationship or love you have for your child who died.

I still miss my child, and desperately want reassurance that they are somewhere safe

Some families seek reassurance that their child is somewhere, and may seek to contact mediums or psychics. Whilst there may be some reputable organisations, we would recommend caution as there appear to be many unscrupulous people offering support to very vulnerable groups of people.

The longer term

The death of a child remains with you forever. Your other children will grow up, and you may wonder what your child would be like now if they were 14...18...21? As the years pass grieving changes and triggers can cause deep emotions to emerge which can catch you unawares. Friends may not refer to your child as much; work colleagues just treat you normally, when life is anything but. You may need to remind people that you still want to talk about your child, to keep their memory alive.

50 *Two to three years on and the future*

"When we have lost a beloved child and endured the suffering with them, we can never be as we were before. We do not necessarily emerge as better people, but we are certainly changed, with different priorities and directions in life"

Mother of a 6 year old boy

Brothers and sisters, when they are growing up and experiencing important milestones such as going to college or university, getting boy or girlfriends, may also start to talk about their brother or sister in more depth. Sometimes they feel guilty that they are achieving something their brother or sister never had the opportunity to do; that they never had the opportunity to discuss with their brother or sister more 'adult' topics of conversation. This is to be expected, and can be an opportunity to talk with brothers or sisters again about what has happened, and to be able to grieve together, and together plan for the future whilst never forgetting the past.

Where do I go for help if I need it?

You can talk to your GP, or contact the hospital, religious advisor, local bereavement services, or one of the help-lines, these are listed in the useful addresses in the contacts section.



Chapter in brief...

- You are likely to still miss your child very badly.
- Brothers and sisters can be particularly vulnerable at this time.
- Only family and close friends will realise how you are feeling. Comments from others can be hurtful.
- You may find it difficult being with other families who are still complete.
- Support is always available. If you need any advice or help, please see useful contacts section at the end of the booklet.



How friends can help

Parents have told us they would like an information sheet to give to friends. This may help them understand what they can do to help after your child has died.

How can I help my friend whose child has died?

Your friend whose child has died may not feel that you really understand their total devastation. Clearly, it is impossible to understand completely how anyone else feels as you are not in the same position. However, you can help them in many different ways. The following suggestions may help you feel you are doing something useful:

- Offering to do practical things like cooking, shopping, washing, ironing. The list is endless. This can take away the burden of having to even think about doing these things.
- Sometimes taking care of their other children, so that your friends can have some time for themselves, either alone or as a couple.
- Driving them, for example, to the shops, when they feel they cannot face the traffic.
- Some friends can listen but others find it too upsetting. If you find you can't listen, it doesn't mean you don't care. Offering to do things instead can help

your friend to feel you are trying to support them.

- Your friend is likely to need more support as the weeks go by, when they begin to feel everyone has forgotten them. People tend to ring and offer support in the beginning. The longer you remain in contact, the more you will be able to help your friend. Frequent but short contacts are really appreciated.
- Your friend may have difficulty in accepting your healthy family. Try not to feel guilty or upset about this. At this time, it is really difficult for them to think about any-one else's point of view.
- Your friend will appreciate honesty and if you want to tell them how difficult it is for you to understand, you can say "I just cannot begin to understand how terrible it must be for you."

It is also clearly devastating to hear that a close friend's child has died. While you were probably told it may happen, no one believes it really will happen, and the news often comes as an enormous shock. Everyone hopes that their child will escape, and be the one who is cured against all the odds. This may make you worry about your own family as well as feeling desperately sorry for your friend and their family. Some people feel guilty about worrying about



those closest to them, however when a tragedy like the death of a child occurs, this is natural.

How can I talk to my friend whose child has died?

- Try not to just say “How are you?” Although very well intentioned, your friend will probably feel the need to say “Fine”. Sometimes comfort can come from simply putting an arm around your friend and saying very little. Or, if you are ready to hear the answer, you can say “How are you really feeling?”
- Try not to say “The good die young” or “God needed him” or “She was too special”. The list of these could be endless and, while there may be truth in some of them, your friend is unlikely to find them helpful.
- Euphemisms such as ‘fallen asleep’ are not helpful. It can be difficult to use the word died, but it is the truth. To say to your friend they have ‘lost’ their child makes them sound careless. The best words are often the ones your friend uses. You will soon pick up how they refer to their child who has died.
- It is almost never helpful to say to someone “You can always have more children”. This may or may not be true. The child who has died can never be replaced. He or she was absolutely unique and individual.
- Try to sit and listen for as long as it takes, accepting what is said rather than giving reassurance or advice. It is exhausting listening to anger, sadness, accusations and guilt. Listening to the same story repeatedly can become difficult but it will help. Telling their story is the main way that people start to grieve. Try to understand that there will be times when your friend does not want to talk and wishes to be on their own.
- Never cross the road to avoid speaking to your friend, even if you feel you want to. This can feel very hurtful. If you do not know what to say, then say so, because at least you are acknowledging the person’s sadness. They had no choice that their child died, but you do have a choice in how to be a real friend.
- Look after your friend’s physical needs. For example, encourage them to eat and get enough rest. You may be able to help them resume activities they had previously enjoyed.
- Talk about your friend’s child in everyday conversation. There may be some bereaved parents who do not want their child’s name mentioned but most do. You will not be reminding them about their sadness, because it is there all the time. Parents will probably welcome the chance to talk about their child for the rest of their lives.

How schools can help

Parents have told us that it would help to have some information to give to their child's school. This is to help them understand what they can do to help both before and after your child has died. They have also suggested it may help to have some guidance for schools about how to talk to the rest of your child's class, and what to do if your child still has brothers or sisters attending school.

It is crucial for schools to remain in contact with any child who is receiving treatment, as school can be such a normal and important part of a child's life. If the child becomes very unwell, then we would always recommend that contact is kept with the family. This will ensure clear communication and the school can act with the family's and child's wishes in mind. To the child, however, any kind of normality can be a great distraction and help them to cope.

We recognise that having a child who is terminally ill in the school will have a huge impact both on the staff and on other pupils. Staff will need to be able to reflect on their own feelings and experiences before being able to help the dying child or other pupils.

What can we as a school do to help when one of our pupils is likely to die?

- Having a liaison person at the school is essential to maintain contact with the

family. This will stop the family having to explain the whole situation again to someone new. The family can trust the liaison person to give out information in the way the pupil and family feel is appropriate.

- The pupil may feel that they would appreciate some contact with the outside world, but can't manage a whole day in school. It may be possible to do a half day or even just a lesson or break time, with a member of staff designated to take responsibility. Schools need to be flexible with these kinds of arrangements.
- If the child is too unwell to manage school at all, perhaps a short visit from a few classmates might be welcome. A tape from them sending special messages may also be well received. This could be monitored and organised by the teacher responsible. The chances are that teachers and classmates will have followed the child's illness from the start. This may make them feel involved and want to help in some small way to make the last days special.
- Emphasise that, even if pupils feel uneasy about seeing someone very ill, they can still remain in contact with telephone, e-mail, videos, texting, MSN, or letters.



- Home tutors can be especially useful as they often have a special empathy for very seriously ill children and their families.
- Always talk with all staff involved before talking to pupils, as staff members may have strong feelings. They have to feel able to manage these feelings and then manage pupils' reactions. Keep those who need to know informed. Try and think about the need for support both for pupils and staff.
- Discuss how to let pupils know what is happening. Think carefully how to talk in classes where there may be a brother or sister. Give siblings a chance to choose whether or not they are present or absent when a class discussion takes place.
- Discuss who is available to support staff and pupils. Think about their availability.
- Make sure that all staff are aware and that there is one key person to remain in contact with the family. Talking to many different members of staff may become too difficult for the family. Make sure too, that all staff are telling the same story.
- It is important for the school community to acknowledge the death of a pupil. This needs to be done in a way that will convey the importance of each individual in the community, and respects the child and his or her family.
- Think about the impact on staff. They should only be asked to speak to classes if they feel able to deal with pupils' reactions and questions.
- Consider telling pupils in small groups if possible. This will allow for questions and expression of feelings.
- Consider how the family would feel about staff or pupils attending the funeral.

What do schools need to consider after a child dies?

Parents usually contact the school after their child has died. Schools often want to have a special assembly or service. Check that it is not too soon, or at a time that is too difficult for the family. This is particularly important for schools where there may be a brother or sister as no-one wants to make the situation more difficult than it is already.

- Consider the policy of the school on staff and pupils attending funerals.
- Arrange for support to be available for both pupils and staff. See end of this 'How schools can help' section for a list of resources/references and booklist.
- Think very carefully if there is a surviving brother or sister and how you will include them in any memorials. Talking with them and their family will ensure the best level

of support is available. Make sure you treat the surviving brother or sister in a way that is acceptable to both the child and the family.

- The school may also feel they would like to make a more permanent memorial to the child in the following months, such as a bench or seat with a plaque or special tree planted.

How to help someone who is going through loss and bereavement

- Let your genuine concern and caring show.
- Be available or arrange for someone to be available for them.
- Allow them to talk about their feelings, both positive and negative.
- Remember, there is **no** right or wrong way to feel after a loss. Everyone will find their own way of dealing with it.
- Don't let your own feelings of helplessness keep you from offering support.
- Don't avoid grieving brothers or sisters because you feel uncomfortable.
- Don't say you know how they feel, unless you have had the same loss. Never tell them what they should feel.
- Don't change the subject when a pupil mentions their loss.

- Don't try to find something positive to say about their loss. This can trivialise it in their eyes.



School references/ booklist

Williams, G (1983) **When people die.** A book for teenagers. Macdonald.
ISBN 0904265765

Richter E (1986) **Losing someone you love.** Putnam. Young people share their experiences about the death of their sibling.
ISBN 0399212434

Grollman, E (1993) **Straight talk about death for teenagers, how to cope with losing someone you love.** .Straightforward book, a guide to talking about death. Beacon Press.
ISBN 0807025017

Couldrick, A (1991) **Grief and bereavement, Understanding children.** Sobell Publications. Very short booklet, explaining how children respond to grief.
ISBN 0951753712

Perschy, Mary (2004) **Helping teens work through grief.** Accelerated development, useful hints for professionals working with teenagers who are/may be bereaved.
ISBN 0415946964

Ward, Barbara (1996) **Good grief,** exploring feelings, loss and death with over eleven's and adults. London Jessica Kingsley publishers. ISBN 185302348

John Morgan (1990) **The dying and bereaved teenager.** Informative book

about the grieving and anticipatory grieving process. Useful different chapters on different aspects of dying and bereavement.
ISBN 0914783440

Romain, T (1999) **What on earth do you do when someone dies?** Free Spirit Publishing. Guide for older children written in a straightforward way, with practical tips and advice. ISBN 1575420554.

Useful resources for schools

Education Authority bereavement officers

Child Bereavement Trust

Provides nationwide training and support for those who care for grieving families, and produces videos for parents and children. Address: Aston House, High Street, High Wycombe, HP14 3AG

www.childbereavement.org.uk

Information & support service line:
0845 357 1000

Childline

24 hour confidential helpline.

www.childline.org.uk

Tel: 0800-1111

Useful support resources

Local resources

Staff at the hospital or community where your child was treated can

provide advice about local bereavement services and other support.

Your General Practitioner (GP)

will be able to let you know about local bereavement services, or referral to child and family services.

The schools your children attend, may also be able to provide counselling or advice.

The chaplain at the hospital or your local religious advisor can offer support and advice.

National resources

Child Death Helpline

Tel: 0800 282986 (freephone)

Website: www.childdeathhelpline.org.uk

Helpline staffed by volunteer parents who have suffered a loss of their child.

The Helpline is available every evening 7pm to 10pm and Monday to Friday mornings 10am to 1pm and Wednesday afternoons 1pm to 4pm.

Children in focus

Specialist service who offer advice and support to families after the death of a child. The service co-ordinates a group of funeral directors who offer reduced or free of charge funerals and who are experienced in helping families after the death of a child. Freephone: 0800 801 4881

Compassionate Friends

53 North Street, Bristol BS3 1EN

Helpline: 0845 123 2304 (10am to 4.00pm and 6.30pm to 10.30pm)

Website: www.tcf.org.uk

For parents who have had a child of any age die.

Cruse Bereavement Care

PO Box 800, Richmond, Surrey, TW9 1RG

Day by Day Helpline: 0844 477 9400

Website: www.crusebereavementcare.org.uk

Cruse bereavement centre offers counselling and support for all bereaved people.

Child Bereavement Trust

Aston House, High Street, High Wycombe, HP14 3AG

Tel: 01494 446648

Information and support service line: 0845 357 1000

Website: www.childbereavement.org.uk

Provides nation-wide training and support for those who care for grieving families, and produces videos for parents and children.

The British Humanistic Association

1 Gower Street, London WC1E 6HD

Tel: 020 7079 3580

Website: www.humanism.org.uk

Represents the interests of ethically concerned but non-religious people.



Cancerbackup

3 Bath Place, Rivington Street, London
EC2A 3JR

Tel: 020 7696 9003

Cancer Information Service:

0808 800 1234 (freephone) or
020 7739 2280

Website: www.cancerbackup.org.uk

Helps patients, their families and friends cope with cancer. Trained cancer nurses provide information, emotional support and practical advice by phone and letter. Over 50 publications on cancer, its treatment and practical issues of coping are available. They also provide information on support groups throughout the country.

CLIC Sargent

Provides information and support for children and young people with cancer and their families.

Website: www.clicsargent.org.uk

Helpline: 0800 197 0068 (9am to 5pm)

Rainbow Trust Children's Charity

6 Cleeve Court, Cleeve Road, Leatherhead,
Surrey KT22 7UD

Tel: 01372 453309 (24hours)

Website: www.rainbowtrust.org.uk

Provides practical and emotional support to families who have a child with a life threatening or terminal illness. They can provide respite care/short holidays.

Relate

Little Church Street, Rugby, CV21 3AP

Tel: 01788-573241 (for information about local services)

Website: www.relate.org.uk

Confidential counselling for families looking at relationships, bereavement or problems of any kind.

Samaritans

Tel: 0845 790 90 90

Website: www.samaritans.org.uk

E-mail: jo@samaritans.org

24 hour emergency line.

Gingerbread

Tel: 0800 018 4318 (freephone, Monday to Friday 10am to 12pm and 1pm to 3pm)

Website: www.gingerbread.org.uk

Provides lone parents with support and advice.

ChildLine

Tel: 0800 1111

Website: www.childline.org.uk

A free 24 hour confidential helpline for children and young people in the UK.

Helpful books

For young children

Stickney, D. (2004) **Water Bugs and Dragonflies**. Pilgrim Press.
Excellent short story using analogy of waterbugs developing into dragonflies for death. Beautiful and easy to understand.
ISBN 0829816240

Varley, S (1994) **Badger's parting gifts**. Lions. Excellent introduction about death, and memories using woodland animals.
ISBN 0006643175

Simmonds, P (1988) **Fred**, Red Fox.
Wonderful fun comic style book about a cat who has died. Good to start conversations about death.
ISBN 0099264129

Maple, M (1992). **On The Wings of a Butterfly**. Parenting Press, Seattle, Wa. A story about Life and Death. This is a gentle way to try to explain to children what happens when someone dies and is a true story about a little girl who has cancer.
ISBN 0943990688

Wilhelm, H (2002), **I'll always love you**. Crown. Short introduction and conversation starter.
ISBN 0517572656

Sims, A (1986) **Am I Still a Sister?** Big A & Company. A lovely book for siblings, helping them to feel valued.
ISBN 0961899506

For older children

Fred, as above

White, E (2003), **Charlotte's web**, Puffin Books. Beautiful story introducing death, in a novel. Ideal to be read over a period of time as a story, or read independently.
ISBN 0141317345

Winston's Wish (2000) **Muddles, Puddles and Sunshine: Your activity book to help when someone has died**. Hawthorn Press. Fantastic activity book offering practical activities and conversation starters for bereaved children.
ISB 1869890582

Heegaard, M (1991) **When someone has a very serious illness**, Woodland Press. Activity booklet to be completed by children, with or without parents. Introduces ideas of change, loss, and support, great to start conversations and to get children drawing out their feelings.
ISBN 0962050245

Heegaard, M (1991) **When someone very special dies**, Woodland Press.
Carries on the work started above, but can be read on its own. Is an activity book to be drawn in and completed by children. Great place to start talking about feelings, and death and support.
ISBN 0962050202



Heegaard, M (1991) **When something terrible happens, children can learn to cope with grief.** Woodland Press.

A work book to help children work out their feelings about a difficult event, helping the child to express their feelings.

ISBN 0962050237

Romain, T (2003) **What on earth do you do when someone dies?** Free Spirit Publishing. Guide for older children written in a straightforward way, with practical tips and advice.

ISBN 1575420554.

Richter, E (1986) **Losing someone you love. When a brother or sister dies.** Putnam. Young people share their experiences about the death of their sibling.

ISBN 0399212434

Gernstein Mordicai (1987) **The Mountains of Tibet. A child's journey through living and dying.** Barefoot Books. Based on the Tibetan teachings of Life and Death.

ISBN 1898000549

For parents

Grollman, E (1991) **Talking about death: a dialogue between parent and child.**

Beacon Press. Straightforward book, a guide to talking about death.

ISBN 0807023639

Couldrick, A (1991) **Grief and bereavement, Understanding children.**

Sobell Publications. Very short booklet,

explaining how children respond to grief.
ISBN 0951753711

The Compassionate Friends. **Help for the family who have lost a child** (see contacts).

Mirren, E (1995). **Our Children.** Hodder & Stoughton. Coming to terms with the loss of a Child - Parents' Own Stories. The Compassionate Friends.

Sister Frances Dominica (1997). **Just My Reflection.** Helping Parents to do things their way when their child dies. From Helen House Children's Hospice. This is an excellent book for suggestions for funeral arrangements and services.

ISBN 0232522111

Rosen, M (2004) **Sad book.** Walker Books
Honest book for children or adults about what makes us sad, but for the author what makes him most sad is thinking about his son who died.

ISBN 0744598982

Holloway, A. (1993) **Matthew - Shadows Soft Around His Name.** (CRUSE)

A journey through grief for a parent.

ISBN 0853053308



The dandelion was chosen as it represents a beautiful cycle of life and death. The dandelion looks fragile, but can be strong and tries to withstand storms and all that nature throws at it. It is an image that children love, and blowing out dandelions gives a simple pleasure which can help promote hope and memories.

Original dandelion illustrations by Sue Harvey.



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CANCER RESEARCH UK



Children's Cancer and Leukaemia Group
Third Floor, Hearts of Oak House
9 Princess Road West
Leicester LE1 6TH

Tel: 0116 249 4460

Fax: 0116 254 9504

Email: info@cclg.org.uk

Registered Charity No: 286669

**CCLG leaflets are available to
download from www.childcancer.org.uk**