



# Precious Times

A handbook on palliative care for parents of children with cancer

## Precious Times

Palliative care for children with cancer – a handbook for parents.

Haematology/Oncology Unit, Children's Health Ireland at Crumlin  
Published: 2000, revised 2004, 2016, 2019

The information in this book was compiled by Frida Lowry, Miriam Mooney, Eddie O'Neill, Sandra Ratcliffe (Social Workers) and Cliona Cronin, Eileen Furlong, Mary Macnamara, Catrina Scanlan (Liaison Nurses) on behalf of the Haematology/Oncology Unit, Children's Health Ireland at Crumlin, Dublin 12. Subsequent editions were edited by Vicky Fourie (Social Worker), Jane Garland (Clinical Nurse Specialist) and Mary O'Rourke (Social Worker), along with their teams.



Published by the Irish Cancer Society

## Acknowledgement

We would like to thank the parents and children who shared their thoughts and experiences with us. Their input greatly enriched the contents.



## Contents

Introduction	2
<b>The start of your palliative care journey</b>	
What will happen next?	4
Questions that may be on your mind	6
Managing symptoms	8
Talking with your child about what is happening	19
Brothers and sisters	21
Coping with the changes	23
Special events	24
Visitors	25
<b>When your child dies</b>	
Some questions you may have	28
Planning your child's funeral	30
Coping with your other children	34
Children's grief	36
Guidelines on children's understanding of death	40
The Siblings Charter	41
Practical matters after your child has died	42
Bereavement support services from the staff on St John's Ward	44
Coping with the days and nights ahead	46
Books which you may find useful	49
Bereavement services and organisations offering support	51

## Introduction

The term 'palliative care' is used to describe supportive care and treatment that is given to ease symptoms and improve quality of life, but with the knowledge that it will not lead to a cure. A palliative care approach means that your child's comfort and dignity become the priority. Most of this care is given at home.

The progression of your child's disease to this stage may have been expected, or come as a total shock to you. Either way, you are most likely feeling devastated. We hope that we, along with family, friends and the professionals you are dealing with, will be of some support to you. You may have questions that seem almost too terrible to ask. We will try to gently address some of these in this booklet.

The purpose of this book is to give you and your family information that will help you during this difficult time. We hope it will help reduce some of the desperation that you might now be feeling on hearing that a cure is no longer likely for your child's illness. It is a book for parents, written with the help of families who have experienced some of what you may now be going through. These parents suggested the title Precious Times.

Some of the issues we cover in this book are extremely sensitive. We have divided it clearly into sections and suggest that you only read some sections for now. Your social worker and clinical nurse specialist (CNSp) are available to discuss any of the issues with you when you feel the time is right. Your child, you and your family are all very important to us. We hope this book and our service will be of some help.

## The start of your palliative care journey...

It is likely that at this point you will be introduced to the Palliative Care Team at Children's Health Ireland at Crumlin. This team includes a consultant in paediatric palliative medicine and clinical nurse specialists. This team forms a link between you, Crumlin and your community specialist palliative care team.



## What will happen next?

One of the first things you need to know is who is going to help you and your family throughout the coming weeks and months. Your child's consultant will meet you and discuss your situation and the options that may be available. There may be treatments available to help slow down the progression of the disease. They may also help with symptoms, but are unlikely to control the disease in the long term.

Whether or not further treatment is available, it is often a good idea for you to get to know the people who can help your child during their last weeks or months. This may be a good time to meet the Palliative Care Team at Children's Health Ireland (CHI) at Crumlin.

Each county has a community specialist palliative care team. These teams are sometimes based in the local hospice, in the grounds of a hospital or healthcare unit, or in a separate location. Each team has a number of specially trained nurses that work with a consultant in palliative medicine. The team guides you through your child's symptom management alongside your GP (family doctor) and public health nurse (PHN). Some teams are larger than others, and include social workers, occupational therapists and physiotherapists. Others are much smaller.

There are also a number of paediatric outreach palliative care nurses who will help you to care for your child. The Palliative Care Team in Crumlin will let you know what is available in your area.

One of the palliative care clinical nurse specialists in Crumlin will contact your GP to let them know what is happening. With your GP's permission, they will do a referral to the community specialist palliative care team.

It is likely your GP will have worked with this team many times in caring for other patients.

A palliative care clinical nurse specialist then contacts the community specialist palliative care team and sends the referral and any necessary documents, such as reports of relevant tests. This team will contact you directly to explain their roles and agree a visiting plan to suit you. This plan can be changed at any time to meet you and your child's needs.

The initial aim is to give you and the team time to get to know each other. Your child can also get used to new people while symptoms are not yet an issue. If your child has symptoms, such as pain, the specialist palliative care nurse will help you to control these symptoms and will speak to your GP about medication. There is also ongoing support available in Crumlin from the oncology or haematology team, and from the Palliative Care Team, as needed. If your child has attended a local shared care unit, they may also be involved from time to time.



## Questions that may be on your mind

### Q *How are we going to cope?*

**A** Your palliative care clinical nurse specialist and social worker will help you to plan the care your child will need now, as most of this care can take place at home. It is important that your community specialist palliative care nurse meets you and your family fairly soon. This makes it easier for you all to get to know each other. You will also have developed a relationship with your specialist palliative care nurse when you need them more. However, some families find this first introduction upsetting, and are not sure when the time is right for them to do this.

We will always try to prepare you for things that might happen leading up to your child's death. If you know what to expect and what to do, it will be much easier for you to cope. Some parents want to know immediately what symptoms their child is likely to develop, even if their child is very well. Other parents do not like to think about these things until later. The timing of these discussions is important. Feel free to let your palliative care clinical nurse specialist know if you want to talk about likely symptoms now or at a later date. (You can also go to page 8 for more information on pain and symptom management.)

*Looking back on it now, I wonder how we coped. I don't know where we got the strength. Maybe all we had gone through, in the three years Karl had been sick, really helped us. We just got on with things without thinking too much about it.*



### Q *How long does my child have?*

**A** This is a very difficult question to answer because each child is unique. The duration of your child's life may depend on the type of cancer. Some children will die within a week or two and some will live for many months. Your consultant may be able to guide you as to how long your child has. Most children die over a period of days and their families are expecting it. Your specialist palliative care nurse, who will see your child regularly, will usually alert you to changes and advise you accordingly. You know your child better than anyone else and it is most often parents who first notice changes. We will have told you what to look out for. It is usual that you will be expecting your child's death and have those who you want with you.

*Not knowing how long my child had left to live was hard at the beginning but I soon learned to just take every day at a time. In the end, the nurse told us that she only had another day or two to live and we were able to prepare ourselves as best we could.*

### Q *Where will my child die?*

**A** This decision is entirely up to you. In our experience, almost all families choose home. This is where most children want to be, surrounded by their family, friends and all that is familiar. Unless there is a medical reason for your child to be in hospital, everything possible will be done to make sure that your child can stay at home. In some areas, your specialist palliative care nurse can arrange for a nurse to be with you overnight if or when this would be helpful. This nursing service is provided by the Irish Cancer Society. Ask your GP if the service is available in your area.

*Being at home was so important for my child. I was terrified at first but soon realised that I wouldn't have wanted her to be taken into hospital. The nurses and doctors had me well prepared at home and life went on pretty much as normal most of the time.*

## Managing symptoms

Before your child dies you may worry about what symptoms they are likely to develop in the palliative care phase. You may have talked about some of the likely symptoms initially with your consultant haematologist/oncologist and clinical nurse specialist in Crumlin. The consultant in paediatric palliative medicine may also have spoken to you about what to expect. Your GP and specialist palliative care nurse will also be able to answer many of your questions as they arise. You may be told about symptoms that never actually occur, but we feel it is important to discuss all the possibilities. If you have information about what is likely to happen and know what to do, the situation may be more manageable and less frightening if it happens.

*I was scared when I was told about what symptoms Joe might get, but it was better to be prepared for the ones he had. Luckily he only got a few.*

### 1 Pain

For many parents, their greatest fear is that their child may have uncontrollable pain before they die. Many children on palliative care do have pain, but most pain can be very well controlled with medication.

Some children have more than one type of pain and may therefore need more than one medication. The team working with you and your child will monitor pain closely and make sure that everything possible is done to control it. As a parent your input is very important as we greatly respect that you know your child better than anyone else. We will always listen to you and your child for guidance in helping to control the pain.

When children complain of pain, they may need morphine or other similar medicines. It is important to consider some issues that may help you to know if your child is in pain and what to do as a result. The following questions and answers may help.

#### **Q** *Why does my child not want to be touched or held?*

**A** Many children who are in pain do not want to be touched, or may have pain when they move. This can apply from infants up to teenagers. The aim of pain control is to get to a point where your child is comfortable being held or being moved around. Controlling pain, so that your child can be held, is very important for your child and for the whole family who have a need to touch and be touched.

#### **Q** *Will my child always let us know that they have pain?*

**A** Many children are aware that saying they're in pain can make their family members anxious or upset. It also brings a realisation for themselves and others that they are not getting better. The reluctance to take more medication may lead them to hide their pain from you too. They may need encouragement and sometimes permission to admit that they are not comfortable.

*I didn't let my Mum or my Dad know when the pain got bad. It just seemed to make them so sad and I didn't want that. I told my dog instead.*

#### **Q** *Are children who are active not in pain?*

**A** Children who are in pain may remain active as they can learn to tolerate their pain, but the pain can be there and be very real. It is important to find a way for you to work out if your child has pain. It is also important to know that most pain can be relieved.



**Q Are injections needed to control pain?**

**A** We are aware that many children hate needles. As a parent it is okay for you to ask that your child does not get an injection. Other ways of giving medicine that work very well are:

- **By mouth.** Some medicines are available as tablets to swallow or dissolve under the tongue, as liquid, as granules to dissolve in water, as a lozenge or as a lolly to 'paint' the medicine on the inside of the cheeks.
- **By nasal spray.** Some pain medicines can be given in this way.
- **Rectally.** Almost all tablets that are given by mouth can be given rectally (putting the medicine into the back passage). This can be a useful option for younger children.
- **Through the Hickman line.** If your child's Hickman line is still in place it may be used to deliver pain medication. This will be discussed with you.
- **Through a sticky patch** applied to the skin.
- **Under the skin (subcutaneously).** Some children will not be able to have their medicines by the routes mentioned above as they come closer to the end of their lives. A small pump can be attached to infuse medicines over a 24-hour period, taking away the need for some, if not all, medicines to be swallowed. Your specialist palliative care nurse will explain how this will work, and prepare you and your child if it is needed.

**Q Will my child need a morphine infusion?**

**A** Morphine can provide great pain relief for your child. However, there are still some myths about morphine, which need to be discussed.

**X 'Morphine affects a child's breathing'**

Morphine does not significantly affect the breathing pattern. In fact, children who have breathing problems can get relief on morphine, as it helps to relieve the sensation of breathlessness.

**X 'Children can get addicted to morphine'**

As long as a child has pain and morphine is given for this reason, your child will not get addicted. As drug addiction is a topical issue and a taboo for many teenagers, your child may need reassurance about taking morphine.

**X 'If morphine is started too soon it will not work at the end'**

There is no limit to the dose of morphine that can be given. It can continue to be increased until the pain is controlled. Many children are on morphine for many months and may continue to go to school, even if they are on large doses.

**X 'Morphine will bring the end nearer'**

Many people believe that morphine given by a pump or infusion will bring the end nearer but this is not correct. Sometimes it's necessary to increase the dose of morphine as the child's condition deteriorates. This can make it seem as though the morphine is speeding up the dying process, but this is never the case. When morphine needs to be started, it does not necessarily mean the end. Some children are close to dying when they need to start morphine. But many are not and can remain active and alert for weeks or months.

## 2 Anaemia

Children who have leukaemia, neuroblastoma or other diseases involving bone marrow, are likely to become anaemic. Your child may become pale and feel tired, needing to sleep more. For most children, this tiredness is not upsetting and it can be the body's natural way to gently wind down. Blood counts are not checked routinely, as these can cause anxiety and dilemmas about transfusions.

Your consultant will discuss whether blood transfusions are helpful. If your child has a good quality of life except for being very tired, a blood transfusion may help this. It is likely that there will be a time when blood transfusions may no longer be appropriate, as it may mean spending several hours in hospital with very little improvement in symptoms. Your specialist palliative care team will guide you with this.

As your child becomes more and more anaemic, they may sleep for longer periods and may even go into a coma, which is usually a deep peaceful sleep. This is likely to happen gradually and you will have some warning. Some children stay in this coma until they die, while others may drift in and out of this deep sleep. Children can hear while in a coma. It is important that you continue to talk to, touch and hold your child during this time as your presence and voice will be reassuring and real to them.

## 3 Nausea and vomiting

Some children have a problem with feeling sick or actually vomiting. It is important to discover the most likely cause, as treatment will depend on this. Children with brain tumours are more likely to have this problem.

There is a variety of anti-sickness medicines that can be helpful, and it may be necessary to give one or more to get good control. Steroids are usually avoided due to their unpleasant side-effects, weight gain and mood swings. However, they may be given for a short period to some children, if necessary. Sometimes it can take a combination of drugs to treat your child's vomiting. Drugs can be given rectally, if appropriate, to a younger child.

## 4 Constipation

All children who take regular morphine are likely to get constipated unless they take laxatives. Regardless of how little your child is eating, they should be having regular bowel movements. If your child normally has a bowel movement daily, you should aim to continue this pattern. It is important to keep a normal bowel pattern.

Freshly squeezed orange juice (with a little brown sugar added) can be helpful for some children's constipation. It is best to use whatever fluids, food or laxatives have worked in the past, but do ask for advice. Signs of constipation can include tummy pains, nausea, vomiting and sometimes diarrhoea (caused by overflow). Let the nurse know if your child is having problems taking the laxatives.

## 5 Loss of appetite and weight

It can be very distressing for you as a parent to watch your child eat or drink less and lose weight. A most natural and basic parental instinct is to feed and nourish your child. A time may come, however, when your child's body is not able to cope with food or fluid and they may have difficulty with absorbing nutrients. This is a natural process. It is important not to put pressure on your child to eat or drink. Excess fluid can cause breathing difficulties nearer to the time of dying.

Treatments such as nasogastric (NG) feeding or intravenous (IV) fluids are avoided as they can be very difficult for the child to cope with. It is also felt that they go against the body's natural needs.





## 6 Infection

If your child has a troublesome chest infection or any other obvious infection, your family doctor may suggest an antibiotic. If your child finds it too difficult to take the antibiotic by mouth, discuss it with the doctor or your specialist palliative care nurse. Intravenous (IV) antibiotics are avoided, if possible, as your child will have to be admitted to hospital for this. This can be traumatic for all the family at this time.

## 7 Seizures

A seizure (also called a fit) is a temporary malfunction of the brain. There are different types of seizures, which can affect your child in different ways. For example, changed behaviour, altered breathing, jerking movements of the limbs, with possible loss of consciousness and incontinence. Not all of these symptoms may occur as it depends on the part of the brain that is involved.

Some children are at risk of having seizures, especially if they had one in the past. Your specialist palliative care nurse will discuss this with you and tell you if your child is at risk and how to deal with the seizure. If a seizure occurs, cushion your child's head and turn them on their side until they recover. It is unlikely to last more than a few minutes. If the seizure lasts longer, it may be necessary to give some medicine either by mouth or rectally. Your team will have prepared you for this. If you need help, phone your family doctor or on-call doctor.

Seeing your child have a seizure for the first time can be very traumatic. However, it is best to stay as calm as possible and to reassure your child. Your child is unlikely to be aware or distressed by what is happening but may be very sleepy for a few hours afterwards. They may have little memory of the event. Sometimes seizures happen towards the end of a child's life. It's important to reassure brothers and sisters that it was not the reason they passed away.

## 8 Bleeding

Your child may have a bleed at some stage. Children who are anaemic and have a low platelet count, may not be at a significant risk of bleeding. However, if bleeding has been an issue in the past, it may continue to be a concern. Your consultant will discuss the measures that should be taken, and whether platelet transfusions are likely to be helpful. There will probably come a time when transfusions will not be appropriate, as your child will need to go to hospital and the benefits only last for a short time.

*I was scared when Jenny's lips were bleeding,  
but I stayed calm, cleaned her mouth and  
we managed quite well*

Even a small bleed can appear large to you or your child due to the bright colour of blood. For this reason, we recommend that you have dark towels and a dark basin available to deal with the blood. Reassure your child that the bleeding will stop. Sometimes the bleed can be controlled by applying outside pressure to the area, as with a nosebleed.

If you notice that there is blood in your child's urine, stool or vomit, tell your family doctor or specialist palliative care nurse when you are talking to them next.



## 9 Difficulty passing urine

Sometimes children are unable to pass urine. Their bladders become swollen (distended), which can be very uncomfortable. If your child has not passed urine for 24-48 hours and is unsettled, you need to contact your family doctor or specialist palliative care nurse. It is important to establish what is happening. Some children stop producing urine as part of the dying process. If your child has a full bladder, the first step is to encourage your child to sit on the toilet (if they can). Try and run a tap at the same time, as the sound of running water is helpful for some children. Placing a warm cloth on top of the bladder area may also work. If the problem continues it is possible that a catheter (tube) will need to be put into the bladder to drain the urine.

The catheter may be left in or taken out immediately afterwards. This tube can be inserted at home by your nurse or doctor. Although it can be a little uncomfortable, it is done very easily and quickly. However, we would like to reassure you that catheters are rarely needed.

## 10 Physical changes

Many parents wonder about the changes that may occur in their child just before dying. They want to be prepared for when they happen. There are some common physical signs that death is near. Your child may experience some or all of them as death draws nearer. These signs include:

- Confusion or restlessness
- Weakness, inability to move on their own
- Incontinence
- Coolness or colour changes in the arms or legs
- Breathing changes – slow breathing or no breathing for several seconds
- Noisy breathing from secretions in the throat
- Decreased vision or hearing
- Coma

Even though you may feel frightened by these changes, your child will not feel any discomfort. They may not even be aware of these changes.

## Steroids

Steroids may have been a very useful group of drugs to use at an earlier stage of your child's illness, but are avoided at this point if at all possible. This is due to their potential side-effects including tummy upset, mood swings and weight gain. Many children old enough to understand are relieved to know that they will not be given steroids unless really necessary.

Steroids are most frequently prescribed for children with brain tumours when the increasing tumour size may cause a rise in pressure and result in nausea, vomiting and headaches. But there are often equally effective alternatives to steroids with fewer distressing side-effects.

For example, painkillers such as morphine may be used to control headaches. There is also a variety of very effective medications available to control nausea and vomiting.

As your child's comfort and quality of life is our priority, these will be used where possible.

Occasionally, steroids may be suggested to help improve your child's appetite or general feeling of wellbeing. While they work this way in adults, in our experience, steroids are rarely helpful for children and therefore not recommended. For children with certain types of leukaemia on palliative care, steroids may be recommended in an attempt to control the disease. This should be monitored closely as we are concerned about their harmful side-effects.

Our policy, therefore, is that if steroids are necessary, they should be given on a short-term basis only and be replaced by an alternative as soon as possible. If your child is prescribed steroids, we recommend that they be given in the morning to avoid restless nights.

## Complementary therapies

There is a variety of complementary therapies available, including reflexology, aromatherapy, music therapy, relaxation techniques and guided imagery, and distraction therapy.

These have given comfort to children and families and may be appropriate for your child. Although such therapies do not provide a cure, many families have reported a sense of empowerment, improved coping and improved quality of life.

*Paul seemed to relax a lot when his brother John gently massaged lavender oil onto his hands and wrists. It also made John feel helpful and involved.*

## Alternative therapies

If you are planning to explore other treatments for your child, please talk to your medical team. They will be happy to support and advise you.



## Talking with your child about what is happening

Many parents are very unsure how best to talk with their child when they receive news that a cure is no longer possible. Given the shock and upset you are likely to be experiencing, it can be difficult to think clearly about how to handle this. As parents, you know your child best and any points that we might suggest are written with this in mind.

A strong desire to protect your child from the knowledge of their condition is a very common reaction. This is often based on the belief that your child would become miserable and unable to enjoy the time they have left. However, as it is likely that your child knew everything about their cancer diagnosis and treatment up to now, they may find it strange and very worrying if that openness stops suddenly. This is especially so if their symptoms are getting worse. Your child will quickly learn not to ask questions if they are not given a realistic explanation for the changes that are now happening.

Most children want to protect their parents and may feel guilty about the upheaval they are causing them and their family. Because of this, some children may pretend they are fine and have no worries, especially when they see their parents upset. Based on your child's level of understanding, we would encourage you to give them a simple explanation of the recent change. They need to know that the cancer won't be cured. It's also important to tell your child that they will be receiving their medical care at home from now on. It may well be that this explanation will satisfy your child for now. However, they will need to know that they can ask questions at a later stage if they want to.

Let your child know that they have done their best and that it's not their fault the illness has come back. This is something they may secretly fear. Some children have very direct conversations about their death. These conversations can be very difficult for parents, who find it hard to know what to say. However, after their child has died, they especially treasure these precious times together. You may initially find yourself taken aback by some of your child's questions about death and react by ignoring or dismissing them.

Do not worry as you can always go back to the conversation with your child when you have had a chance to think about what you want to say.

*Many children are fearful of being on their own as death approaches. Reassurance from you that you will stay with them and will always remember them will help ease their fears.*

HOSPICE NURSE

Nearly all parents of children who have died believe that their child had some understanding of what was happening. This is often based on their child's comments and expressions. You may have precious opportunities to share feelings with your child without directly mentioning death and dying. We would encourage you to create openness with your child so that they can share their thoughts and feelings if they want to.

It is perfectly understandable and normal to feel unable to cope with such chats at times. But it is important not to deny what your child may be saying about their condition. Try not to give your child unrealistic expectations that they will be better soon. While you may not feel able to talk with your child about all their fears and worries, they may talk to and open up to other people. Indeed, your child may feel at times that they do not want to burden you. Try to give your child opportunities to talk with other trusted adults. Your social worker and specialist palliative care nurse will be very willing to discuss these issues and concerns with you during the days ahead and try to answer whatever questions are on your mind.

*When Catherine said she did not want any more chemo and that she knew that she was dying, I wanted to tell her she would be fine. However, I remembered being encouraged not to deny it but it was very hard to do this. I asked Catherine if she was afraid and she said No. I told her that we would be with her all the time.*

## Brothers and sisters

It can be hard to focus on your other children at this difficult time. However, it is important to include them as much as possible now and help prevent regrets later on. Brothers and sisters do need some information about what is happening based on their age and level of understanding.

Try to spend a little time with each of your children daily, if possible. Let them know that care will be given at home now and explain why. Your children may feel some relief at having you all at home and not in hospital. They may need to be told that they can behave naturally with their sibling.

*Even as Paul got weaker it was great to see Laura joking and fighting with him, as they always had done. I am glad that I told her to be herself with him.*

They need to know that they are not responsible for the illness returning or for any symptoms. They may have hidden worries about this. It may be helpful if you explain your sick child's behaviour towards them in terms of their symptoms. For example, your child may have some pain and be irritable or want peace and quiet. Your other children need to know that they are not causing these symptoms, but that they are caused by the illness. Where possible, encourage all your children to help care for their sibling. For example, bringing them drinks and reading to them. This will help them to feel involved and important.

As your child comes closer to death, it is important to prepare brothers and sisters as much as possible. Ideally, older children should be told that their sibling is dying. It can be helpful to find out if they want to be there at the time of the death, or if they want to be woken up if the death takes place during the night. They need their own opportunities to say goodbye in their own individual way. With younger children, it may be wise to wait until the final few days before telling them what is happening as concepts of time and waiting can be difficult to grasp at that age.

Sometimes teenage brothers and sisters cope by spending much of their time out of the house. Some continue to go to school, both as a distraction and as a way of coping with the weight of what's going on. However, try to make a special effort to include them in the caring. This may help them have fewer feelings of guilt and regret. Your sick child may confide in their brothers, sisters or friends about their fears and worries, so it is good that they feel well informed and have ongoing chats with you.

There are a lot of changes happening in all your lives now. There may be situations where teenagers use their friends as a source of support. However, it would also be helpful to ask a trusted adult to pay particular attention to brothers and sisters and to be available to talk over their concerns and fears if they so wish.



## Coping with the changes

Many parents feel a great amount of turmoil during this difficult time of change and upset. You may find it hard to enjoy the days your child is feeling well as you may feel a dark cloud hangs over them. Some parents live each minute at a time, not thinking too far ahead. It can be hard to balance the needs of your child, other family members and your own needs.

Some parents choose to stay working full time in the early days of palliative care and this can help to maintain some routine. Other parents choose to spend more time at home. Be flexible when making these plans. Always take into account your child's changing condition and what is best for all. Do call on the supports available to help you with these decisions.

*After we talked with the social worker it became clear that we should try and openly discuss together how we were going to manage. This certainly helped us get through the changes over those weeks.*

It can be helpful to consider what aims you and your child have during the period of palliative care. Many children are very keen to return to school and in most cases this is possible, even for short periods. Discuss this with the school principal and class teacher before your child's return. As many children may have previously experienced restrictions due to chemotherapy, they especially treasure this new freedom. But this can be difficult for parents. Your child may wish to continue spending time with friends and being out and about for as long as they are able. It is important to allow your child have as much freedom as they wish during this precious time. You may find it tough when your child is out of your sight. However, most children really benefit from doing as many normal activities as possible, for as long as possible.

You may want to seek help from the team as to how to tell friends and family that your child is no longer getting curative treatment. Many parents find it difficult to cope with how upset everybody else is. Grandparents may be particularly distressed and may feel guilt and anger. As death approaches, you may feel exhausted. Try to take some time to rest and spend time together as a family.

## Special events

You may want your child to make their First Holy Communion, Confirmation or to participate in other special events early. You can join with a local school group or have a private ceremony. Most priests and clergymen are very accommodating. However, planning such important events may cause your child to ask some questions. You will need to give some thought to how you will explain your plans.

Many well-meaning people may encourage you to head off on a major trip to, for example, Disneyland. Some families can feel under great pressure to agree to go. However, this is often not in the child's best interest. We would suggest you consider this carefully as such trips can be stressful and it may not be what your child really wants. They may prefer to spend time doing normal everyday things such as going to school, local football matches, shopping, watching a movie, or planning a family day or weekend away. It is important that brothers and sisters aren't left out of these plans. If you are thinking of a long journey, discuss the implications and practicalities of it with your specialist palliative care nurse or social worker.



## Visitors

You may find many people calling to your home when they hear that your child is dying. This can be draining and stressful. Tell people if you would prefer them not to call as often. It is your home so do continue to decide what is best for you all. Your child may need you to protect them from visitors they find intimidating or tiring. Your child may also feel they are on view, with people staring and talking over them. Your other children may feel it is no longer their home if it is constantly full of visitors. It may reduce the amount of time and energy you have for your child.

Many parents find it useful to filter their calls. Consider asking a trusted friend or relation to be responsible for informing others of your child's condition and whether they should visit. People often want to help but don't know how. Asking friends to do housework, errands, shopping and school runs can benefit all.

## Making memories

You may like to create a keepsake for your family – such as a memory box, family tree, or hand and foot moulds. Talk to your specialist palliative care nurse about ideas and services available – such as memory-making at LauraLynn.





When your child dies...



## Some questions you may have

### Q *What do I do when my child dies?*

**A** This is a very precious time so do not rush to call people when your child dies. There is nothing that has to be done immediately. Many families decide to spend some time with their child before telling relations and friends. You may find it comforting to lift and hold your child. This time is your time and can be used to simply sit with your child alone. When you feel able, you may wish to wash and dress your child yourself or you might want the nurse or a relative to help you, or do it for you. Putting a nappy or pad on can help. Choosing what your child wears is entirely up to you. Many children wear their favourite clothes.

Some children ooze a little blood from their mouths or noses when they die. This is nothing to be alarmed about and most parents wipe it away, as they would have done anyway. If your child has a Hickman line in, it stays in place. You do not need to call the funeral director until you have considered your options. You may contact your priest or minister at a time that suits you. Having your child embalmed is not usually necessary (see page 31).

Some families decide that their child should stay on their bed or on the sofa after they have died. Many parents also like to sleep with or lie beside their child. Some want to take a photograph or cut a lock of hair to keep. It is also possible to take a print of your child's hand or foot, as a keepsake. This is something other children in your family can help with. Pressing your child's foot or hand onto an inkpad lets you take a print that you can keep forever. This can be arranged for you in Crumlin hospital.

Your family doctor will usually see your child after they have died. Call him or her when you are ready, as they will sign the death certificate. There are more details about this on page 42.

### Q *How long can my child stay at home?*

**A** Most families keep their child at home for two nights. Your child does not have to spend a night in the church but can do if you so wish. A lot of families find this couple of days extremely useful in helping them come to terms with the finality of what has happened. It is vital that close family can take time, on their own, to be with your child. This may be particularly important for brothers and sisters. It can also help younger children to grasp that their brother or sister is not going to 'wake up' again.

*Keeping Patrick at home on the sofa for the three days after he died, is one of our most precious memories. We all had the chance to say goodbye. So many people came the first day or two yet we all had time on our own with him. It just seemed so right.*

### Q *When should my child be placed in the coffin?*

**A** When you have laid out your child, they can then spend two or three days with you at home on the bed or couch. After this, it is totally up to you to decide who will place your child in the coffin and when. There is no need to do this until just before leaving the house. Having your child on the sofa or bed until then will give you easier access to them. Many parents wish to lift their child into the coffin themselves, continuing their tending and caring to the very last. Others prefer to ask someone else to do this. The lid does not need to be put onto your child's coffin until just before the funeral. Again, it is up to you to decide who does this.

*We were glad that we kept Catherine at home for the two days after she died. We felt that we were keeping our promise not to leave her.*

## Planning your child's funeral

Planning your child's funeral will be one of the final and very painful tasks you will do for your child. There are many aspects to consider and it helps if you can talk over your wishes and make plans together as a family. Different cultures and faiths have their own traditions relating to death. We appreciate that special arrangements for different religions must be made. Therefore, some of the following points may not apply to your situation. Do feel free to discuss your wishes, which we will completely respect.

It is not uncommon at the time of death for extended family and others to take over in an effort to help you out. It may be difficult for you to think straight, and you may find yourself agreeing to others' suggestions. This is why some parents have found it helpful to discuss their wishes in advance. Others, however, only feel able to talk over plans at the time of death. Take time in making these decisions.

Your child, before dying, may also have shared particular wishes with you. Some children choose the music they want at their funeral, the clothes they wish to be buried in or the type of service they want. If you have other children, include them in the discussions. They may like to be involved and may have special wishes, tributes and contributions to make to the service. Prepare them also for what to expect at the funeral.

The following points may help you gather your thoughts:

- Most families choose to keep their child at home in the family setting. You don't need to put your child into a coffin while they are at home. Your child can lie on the sofa, where it is easier to hold, touch, sit or lie beside them. This will make it much easier for your other children to spend time with their sibling, if they wish.

*The best thing we did was keeping Mary at home for the couple of days. It was very special as we all got to say our goodbyes in our own way.*

- Make sure you and your children have time to yourselves as a family, without visitors and callers. These two or three days after the death are precious.
- Talk to your undertaker about the types and colours of coffins available. Some parents choose a white coffin for a child. The undertaker will be able to advise you on the most suitable size.
- It is not usual or necessary for a child to remain in a church or funeral home overnight. Most children are taken directly from home to the church for their funeral service and burial or cremation directly afterwards.
- Depending on your child's age, it may be possible for you to use your own car rather than a funeral hearse. Some parents choose to carry the coffin on their lap while others have used the back seat of their car. Some families choose to walk from their house to the service.
- You may wish to consider putting a funeral notice in the newspaper or inform your local radio station of your child's death.

## Embalming

Embalming is a procedure that uses chemicals to preserve the body. Funeral directors offer the service but it is usually not necessary. Your specialist palliative care nurse will help to guide you, as there may be circumstances where it is helpful. For example, if there will be a long delay between your child's death and the funeral. Embalming will involve taking the child to the funeral home for a period of time.

Some parents choose to talk to the funeral directors before the death and discuss options then, others choose to wait. Early discussions can be helpful so that you can consider all possibilities and make a decision that suits you and your family's circumstances and beliefs.

## Burial

In selecting your child's grave you may wish to consider purchasing a family grave where you can be buried too. Many parents get some consolation from making such a choice. Selecting a graveyard close to home is also a consideration as you may wish to visit the grave frequently. When choosing a funeral director, check whether they have access to the cemetery you prefer. Many families who go to the graveyard before the funeral feel more prepared for the burial. It can give brothers and sisters a chance to see where the coffin will be placed. Many parents put a simple cross on the grave while they take their time picking the headstone they want.

## Cremation

You may decide to have your child cremated. This is available in Dublin, Cork, Cavan, Clare and Belfast.

### Dublin

**Glasnevin Crematorium**

Tel: 01 882 6500

**Mount Jerome Crematorium**

Tel: 01 497 1269

**Newlands Cross Crematorium**

Tel: 01 459 2288

### Cavan

**Lakelands Funeral Home and Crematorium**

Tel: 049 436 2200

### Cork

**The Island Crematorium**

Tel: 021 486 4000

### Clare

**Shannon Crematorium**

Tel: 065 671 3088

### Belfast

**Rose Lawn Crematorium**

Tel: 048 904 48342

Removal to the crematorium may be direct from home or can follow the funeral service in the local church. A service is also held in the crematorium. The ashes will be available in an urn about a day or two following the service. You can choose to take them home and keep them, bury them in a family grave or distribute them in a favourite place. If you choose the latter, bear in mind that some family members may like to keep some ashes in a smaller urn and place them in a grave.

There may also be a wall of remembrance at the crematorium. Here the urn is placed behind a stone bearing your child's name. This ensures that there is still a specific place where you can pray or remember, perhaps at anniversaries or birthdays. The staff in the crematorium will guide you on the options that are available. It is worth noting that the amount of ashes is likely to be small in the case of babies who are cremated.

## The funeral

Your child's funeral service can be a memorable family occasion where you can express what you want about your child. You may opt for a small private service or a more traditional church ceremony. As a family, talk over the music, readings, offerings, gifts, poems and photos you would like at the service. Let your priest, minister or religious adviser know your wishes.

Listen to what your other children say and respect their choices. Some may like to do a reading or bring up the gifts, others may find this too emotional. The school may also be willing to participate (should you wish) by providing the choir or a guard of honour. There is a lot of scope for you to make this day what you want it to be. Some families print their own leaflet for the funeral with special readings and poems on it.

Discussing alternatives and making choices can help you to reduce your feelings of helplessness and encourage you to regain some control. Your involvement in these discussions may ultimately help you to grieve for your child.

*The decision to put John's photo on his coffin during his funeral service added a very special touch and helped us to feel closer to him.*

## Coping with your other children

This section refers mainly to brothers and sisters. However, it may contain some advice for any children that were important in your child's life. For example, cousins, neighbours and young school friends. If you have other children, remember that they may all feel the pain differently.

### Brothers and sisters

Children's reactions to death will vary greatly depending on their age and stage of development, and whether they have had any previous experience of death. Children have to cope with the strong and powerful emotions that are all a part of grieving. Some children are more open and able to express their feelings than others. Try not to have particular expectations of how your children will grieve or should grieve, but rather encourage them to grieve in their own way.

### Breaking the news

Ideally, it is best for you, as parents, to break the sad news to your other children. Often they will have been present when their sibling died. But if not, break the sad news openly and simply and explain it in a way that each child will understand. Do not be afraid to use the word 'dead' when talking to your children. Explanations such as 'gone to sleep', 'passed away', and 'Holy God took him' can all leave too much to the imagination and may cause unnecessary fears.

It will also help over this early period to talk with the children about what will happen and what to expect at the funeral service. Giving them the choice to be involved and included is what matters.

Your children may need encouragement to cry and talk openly, rather than to be strong and brave. Involve and include them as much as they wish and as their age allows.

## Selecting a key adult

You, as parents, may feel very stressed and burdened at this time. For this reason it may be helpful if an adult, perhaps a close relative or friend, took the other children 'under their wing'. This person may offer much-needed support and create the opportunity to share feelings and answer questions. They can also reassure the children and help them understand that it is all right for mammy and daddy to cry and be sad. However, you should discourage your relative or friend from taking your children out of the house for prolonged periods. Your children need to feel involved and included, yet not burdened.

### Quiet private time

Being able to spend quiet undisturbed time with their dead sibling is an opportunity that can be very special for brothers and sisters. They may wish to have their own private few words and may find it comforting to write a goodbye note or place a toy, keepsake or drawing in the coffin. These are all just different ways of saying a personal goodbye.

While you might feel this will be too frightening for your children, the experience of other families shows that involving brothers and sisters can be very helpful. By being involved, your children are more likely to draw comfort and have fewer regrets. It also very much helps to make the death more real for them.

*Michael and Sarah were very scared at first, but by the afternoon they were running in and out of the room talking to her.*

## Children's grief

Children are often less obvious in their pain and they can appear to switch in and out of their grief. It may be many weeks or months before a child expresses their feelings of loss. Each child in a family will have different needs, at different times. This may well have to do with their own relationship with the child who has died. One child may have been especially close to their dead sibling and is therefore losing a best friend too. Alternatively, if there was conflict between the children, your child may now feel guilt. Parents' own approach, attitudes and willingness to be open will also impact on and influence how each child grieves.

### Loss

Many children experience a powerful feeling of loss, desperately missing their sibling. They may also sense the loss of their parents, who are so consumed in their grief and unable to give them much attention. Brothers and sisters may greatly miss familiar family routines and feel confused at times.

*It was Christmas, 8 months on before Michael ever cried. Once he started, he kept crying for days. This was the first time he said he was sad and missed her. We took out her toy box and talked over our memories together.*

### Guilt

Guilt is something that most children feel from time to time. It can happen when they have happy carefree feelings or when they remember having been jealous of their sibling. They may also feel guilty that they have survived and inadequate because they cannot stop you feeling sad. Also, many children secretly worry that they somehow caused the death.

## Fear and anger

Feelings of fear are common. They may fear dying themselves or anything happening to their parents. Your children may not want you to go out without them. They may be fearful of the dark or sleeping alone. Anger is another strong emotion commonly experienced as part of grief. They may feel anger at their sibling for dying and leaving them. Many children may also feel anger towards their parents, God, or the hospital, for letting their brother or sister die.

### Loneliness

Many children keep feelings to themselves and don't share the burden with anyone. Their silence may be puzzling, but this is their way of expressing themselves. Giving them regular opportunities to talk is important. However, some children wish to protect their parents, which may stop them from sharing their sadness. They sometimes feel it is their responsibility to make up in some way for the loss.

## Physical symptoms

It is not uncommon for children to show signs of strong emotions through some physical symptoms. For example, headaches, tummy pains, tiredness, poor concentration or disinterest and behavioural changes. The odd nightmare or bad dream is not uncommon for some. Others may be reluctant to go to school or may show signs of regressive developmental behaviour, such as bed wetting in an older child. Also, some parents have found that they become over-protective of their other children, after a child dies.

*We found that we were over aware of our other children's health after Anna's death and would bring them to the GP for what turned out to be minor or non-existent ailments.*

## What helps?

A lot is expected and demanded of you all during this time of great grief. The following points may help you to cope with your children during the difficult days ahead:

- Regardless of age, good communication helps. It is helpful to be open and honest and share feelings. Being open about your sorrow and tears will give your children the message that they too are allowed to be sad. They will need reassurance that they don't have to be brave and will need patience, understanding and support to help them in all they are going through.
- Continue to talk about and remember your child. Share memories and keep the door open for questions. Different family members may remember the child in their own individual way. They will need space and sensitivity to do this.
- Encourage your children to be themselves. Let them know you love them and that they are special to you.
- Allow the children to visit the grave as they wish but don't insist if they are reluctant to go.
- Making up a photo album of special memories can be a nice way of drawing memories together.
- For some children, sharing your faith may offer some support, for example, saying special prayers.
- Encourage your children to participate in bereavement and remembrance services, but do not insist, if they are not interested.
- Talk to their school teacher so they can be aware and sensitive to your child's needs. This is helpful not only after the funeral but on an ongoing basis as well. Very often stress may present itself unexpectedly and their teacher may be very well placed to offer support.
- Be aware that grief is normal and the pain and sadness will last a very long time. If, however, you are concerned about one of your children, you may wish to seek help from your family doctor, school teacher, social worker or clinical nurse specialist.
- Valuing the children left behind and taking an interest in their lives and activities can help them feel more special and less vulnerable. The death of a child has a huge impact on brothers and sisters. Parents are often aware of this and yet, in the initial period, may be unable to respond to their needs.

*Looking back we can now see how little we noticed Clare's upset. I suppose we were so sad and tired ourselves that we just couldn't see it.*



## Guidelines on children's understanding of death

Bear in mind that every child is different and their understanding of death will depend as much on past experience as on age itself.

### Birth to 2 years

Babies and very young children will experience a sense of loss when their sibling dies, but they will not be able to understand why this is so. They will sense the change in atmosphere and they may lose their sense of security. You may notice that they go off their food, cry more or are more attention seeking.

### Pre-school (age 2–5 years)

This age group does not understand what death really means. It is a very questioning age and you may find yourself answering the same questions to them over and over again. They may expect their dead sibling to come home, as if they were away on a trip or a holiday. They can swing from being happy and playful to being very sad. You may notice some regression in their behaviour. For example, a return to thumb sucking, bed wetting or temper tantrums. Plenty of patience and understanding and keeping to routines should help.

### National school (age 6–11 years)

This age group has a developing understanding of death. They see it as something that happens only to other people. They need factual, honest and simple explanations. You will notice that they too can slip in and out of their sadness. Schoolwork may suffer for a while, though not necessarily immediately. They may complain of tummy aches and pains occasionally.

## Adolescents (12 years +)

This group is very aware of the raw reality of death. They may hide their emotions or not talk about them. They are very aware of peer and friends' reactions. You may notice moodiness, arguments, detachment, a 'don't care' attitude, feelings of depression and a changed attitude to school work. Keeping the door open for communication and offering reassurance can help. An adult outside the family, with whom the teenager relates well, can also be a good support.

### The Siblings Charter

#### Attention mums and dads: Tips from children

- We don't always feel like talking about our dead brother or sister as much as you do, but that doesn't mean we're not thinking of them. Sometimes it's hard to talk about our brother or sister because it makes us feel sad.
- When we go to bed at night, we can get lonely thinking about our brother or sister and sometimes we cry on our own.
- We would like to get a choice about going to visit the grave.
- We would treasure something special that belonged to our brother or sister.
- We would like our photo up on the wall alongside our brother's or sister's.
- Please don't compare us with our dead brother or sister and tell our teachers not to either.
- We will always remember and miss our brother or sister.

*Written by brothers and sisters at an oncology bereavement day run by Children's Health Ireland at Crumlin.*



## Practical matters after your child has died

Following up on the practical matters associated with your child's death may be very difficult and upsetting for you. Those close to you can help by making phone calls or keeping appointments on your behalf. They can also cancel allowances and clinic appointments as necessary when your child has died.

### Financial

Funerals can be very expensive and undertakers' costs can vary. It is worthwhile considering two or three different companies before making your choice. If you are on a low income, the Department of Employment Affairs and Social Protection representative (formerly known as community welfare officer) in your local health centre or social welfare office may be able to help with some of the costs. This allowance is means tested so the amount given will vary accordingly. There may also be charitable assistance available to help with funeral costs.

### Registering the death

It is necessary for you as parent or legal guardian to register your child's death within three months in order to get a death certificate. You do this at your local civil registration service. This can be hard for you emotionally. It may be helpful to bring a friend with you for support. You will need to have photo identification and PPS numbers with you.

If your child died in hospital you will receive a letter from the hospital with a death registration form incorporating a Medical Certificate of the Cause of Death. The doctor fills in Part 1 of the form. Parents complete Part 2 and bring it to their local civil registration office when registering the death. The civil registration service is part of the Health Service Executive and there are offices throughout the country in each city and county. Contact numbers are attached to the letter you receive from the hospital.

## Cancelling allowances

You will need to notify the Child Benefit Section in the Department of Employment Affairs and Social Protection of your child's death. Your local post office will have a form for you to complete and you will need to enclose a death certificate.

If you have been using a medical card or a long-term illness card, you can notify your local HSE office.

If you have been in receipt of Domiciliary Care Allowance or claiming social welfare payments for your child, you can notify your local office of the death and payments will continue for six weeks after the child's death. You, or a family member or friend, can cancel the payment. Remember to send a death certificate or a copy of it to cancel the payment.



## Bereavement Support Service from the staff of St John's Ward

A member of staff involved in the care of you and your child will make phone contact in the days after their death. Other members of the team will ring over the following days, usually your social worker, clinical nurse specialist, and your consultant.

Unfortunately, we are not in a position to send a representative to every funeral, due to the distances involved.

However, we offer a Bereavement Support Service through which we can stay in contact with you for some time after your child dies and during the difficult time ahead. Your social worker and clinical nurse specialist will be the principal contacts in this service. It is up to you if and when you want to use the service. There are a few different parts to the Bereavement Support Service. We have found that some families take up parts of the service, others use none, and some use all of the service.

In the month after your child's death, your social worker will be in contact to offer support over the phone. After that, you can choose what level of continued phone contact you would like with your social worker.

Your social worker can also send you some reading material on bereavement, including reading material and workbooks for your other children.

Some parents like to return to the hospital to meet the consultant and other staff members. This usually happens months or sometimes even years later. The social worker or your clinical nurse specialist can arrange this at a time that suits you. This can be a valuable visit as you may have unanswered questions, which you would now like to ask. It can also give you a chance to meet some of the ward staff you knew over the period of your child's illness.

The Social Work Team organises a Bereavement Information Day for parents twice a year, which is run in conjunction with a sibling programme. This takes place in a venue outside the hospital.

The hospital maintains a 'Book of Remembrance' in the hospital chapel where the name of every child who has died is inscribed. There is also an annual Book of Remembrance Service, which is interdenominational and held at a venue outside the hospital.

You will receive an invitation to these events. In providing the Bereavement Service, we aim to help you make sense of the events around the time of your child's death and to accompany you through the difficult months and years ahead.



## Coping with the days and nights ahead

The sadness experienced by families when a child dies is both devastating and long lasting. For a short while after the death, you may be very busy with visitors calling and funeral arrangements. It is often only after this period of frantic activity that you begin to have time to think. Most parents' initial feeling is one of shock.

The death of a child is one of the worst things that can happen to anyone and no one can tell you how you will feel. There is no 'right' or 'normal' way to feel at this stage and you may experience a wide range of emotions. Sometimes people feel a sense of relief, but they can feel guilty and confused by this emotion. Being relieved that the situation you have struggled with is over is not the same as being glad that someone has died.

It is not unusual for parents to feel that they are going mad following their child's death and occasionally parents talk about seeing, smelling or feeling the presence of their child. Parents describe feelings of disbelief, numbness, anger, sadness, emptiness and loneliness. All these emotions are common and can come and go at different times. Sometimes these feelings are so strong that it can be frightening and overwhelming. Medication may be offered at this point but this may not help you to cope with your grief.

Finding it hard to think clearly or concentrate, memory loss and being prone to accidents are common features, but are not permanent. The most reported symptoms of grief are probably physical and emotional exhaustion. Some parents describe having pains and symptoms similar to those previously experienced by their dead child. To compensate for this, you need to be kind to yourself and take whatever time you need to look after yourself. You may find that you have a lot of time to spare, having previously been very busy. If you feel you have too much time on your hands, it may be useful to plan to do specific things. For example, enjoyable physical exercise or meeting friends.

Often people feel compelled to make major and dramatic changes in the months after the death of their child. Sometimes they regret this later. Experience and research suggest that it is best not to make any major long-term decisions in the first 12 months following bereavement. Most people find that their views and opinions can frequently change during this period. Well-meaning friends and relatives may put pressure on you to choose a headstone and send out memorial cards shortly after your child's death. Do these at your own pace and try not to feel rushed.

Grief can be a lonely and isolating experience. You may expect your partner to be a special help at this time. However, this doesn't always happen because everyone grieves in different ways and at a different pace. It is often necessary to accept this and give each other time and space.

*Dads are expected to be the strong ones. They hurt too but all the help and sympathy can be directed at the mother.*

Some parents find that by visiting the grave they feel close to their child, while others feel the closeness elsewhere or sometimes nowhere. If your partner doesn't share your feelings about the grave it doesn't mean that they are grieving any more or less than you. It simply highlights the different ways each person experiences a loss.

Sometimes the reactions of relatives, friends and neighbours can be distressing. They too are experiencing a loss and may be unsure of what to say, or even make inappropriate comments. Often they may try to avoid you or appear not to be able to talk about your child. They might just need to know that it's safe to talk about him or her. Often all that is needed is for you to start the conversation.

You may feel under pressure from yourself and others to 'return to normal'. Don't let this pressure influence you too much on decisions such as returning to work or taking up a new job. There is no hurry to sort out your child's room, clothes or toys so wait until you feel ready for this. If the room has been tidied, or your child's clothes washed immediately, this might lead to regrets afterwards. Some people like to be surrounded by photographs of the child, others less so. Do what is comfortable for you and your family, bearing in mind that everyone's needs may be different.

We will send you literature on bereavement. Some parents find it helpful, as it highlights that their feelings are normal. Some people decide to put off reading about bereavement for the time being. It is often impossible for parents to imagine that the distress they feel in the months and years after the death of their child will ever ease. During this period you may find your faith a great help. However, many find they question their beliefs and lose faith. This may be a temporary experience. Other parents have discovered that, in time, the awfulness of the grief subsides, while the sadness remains. Most people have found that talking to someone, perhaps another bereaved parent or close friend, can help to bring some comfort and reassurance.

This book aims only at guiding you, your family and your child at a time that is very traumatic and bewildering. It is not a book to be read in isolation. The team on St John's Ward and your local team will follow up on all issues that arise for you while you are reading it. Your child is very important to us. We hope this book and our service will be of some help.

***Be proud of your child and their courage. They are an inspiration to many people.***

## Books which you may find useful

### Young children

*When Someone Has A Very Serious Illness* (1996)  
Marge Heegaard, Woodland Press

*Badger's Parting Gifts* (2019)  
Susan Varley, London: Andersen Press Ltd.

*Water Bugs and Dragonflies – Explaining Death to Children* (2004)  
Doris Stickney, Pilgrim Press, Cleveland

*Remembering My Brother* (1996)  
Ginny Perkins, A&C Black Ltd, UK

*On the Wings of a Butterfly, A Story about Life and Death* (1992)  
Marilyn Maple, Parenting Press

### Older children and adolescents

*Common Threads of Teenage Grief* (2005)  
Janet Tyson and Teens Who Know, Helm Publishing

*Charlotte's Web* (1963)  
E.B. White, Puffin Books

*Straight Talk about Death for Teenagers – How to Cope with Losing Someone You Love* (1993)  
Earl A Grollman, Beacon Press: Boston

### General reading for adults

*Managing Symptoms at Home: Palliative Care Information for Families* (2010)  
Alison Dowsett and the Paediatric Oncology Palliative Care Team, Cambridge University Hospitals Foundation Trust in collaboration with the CCLG Publications Committee

*The Bereaved Parent* (1977)  
Harriet Sarnoff Schiff, Human Horizons Series:  
Condor Book Souvenir Press Ltd

*When Bad Things Happen To Good People* (1981)  
Harold S. Kushner,  
Avon Books: New York

*Talking about Death — A Dialogue Between Parent and Child* (1990)  
Earl A Grollman,  
Beacon Press: Boston

*Rachel's Story*  
Published by Veritas and available from Veritas bookstores

*A Broken Heart Still Beats* (1998)  
Anne McCracken & Mary Semel,  
Hazelden Foundation, UK

## Books on helping children through bereavement

*Helping Your Child Through Bereavement* (2000)  
Mary Paula Walsh, Veritas – available from Veritas Bookshops

*Healing A Teen's Grieving Heart, 100 Practical Ideas For Families, Friends And Caregivers* (2001)  
Alan D Wolfelt, Companion Press, USA

*Lifetimes* (1998)  
Bryan Mellonie and Robert Ingpen, Bantam Books

*When Someone Very Special Dies* (1996)  
Marge Heegard, Woodland Press

*The Next Place* (2002)  
Warren Hanson, Waldman House Press

*The Day the Sea Went out and Never Came Back: A Story for Children Who Have Lost Someone They Love* (2003)  
Margot Sunderland, Nicky Hancock, and Nicky Armstrong, Speechmark Publishing

## Mobile apps



*Headspace*

*Child Bereavement UK*

*GriefSteps*



## Bereavement services and organisations offering support

If you feel the need to make contact with a local bereavement service, your social worker or clinical nurse specialist from St John's Ward will be happy to point you in the right direction. Your specialist palliative care nurse can also help.

Some of the following organisations may be relevant to your needs:

**Anam Cara** (Parental and sibling bereavement support)  
[www.anamcara.ie](http://www.anamcara.ie)

**The Barretstown Bereavement Programme**  
[www.barretstown.org](http://www.barretstown.org)

**Irish Hospice Foundation**  
Tel: 01 679 3188  
Email: [info@hospicefoundation.ie](mailto:info@hospicefoundation.ie)  
[www.hospicefoundation.ie](http://www.hospicefoundation.ie)

**Irish Cancer Society**  
Cancer Nurseline  
Freephone: 1800 200 700  
Email: [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)  
[www.cancer.ie](http://www.cancer.ie)

**The Bereavement Counselling Service**  
(Adult, Children and Family Bereavement Counselling)  
Tel: 01 839 1766  
Email: [bereavement@eircom.net](mailto:bereavement@eircom.net)  
[www.bereavementireland.com](http://www.bereavementireland.com)

**Barnardos Children's Bereavement Service**  
Tel: 01 473 2110  
Email: [info@barnardos.ie](mailto:info@barnardos.ie)  
[www.barnardos.ie](http://www.barnardos.ie)

**Rainbows Ireland**  
(Bereavement Group Support for Children)  
Tel: 01 473 4175  
Email: [ask@rainbowsireland.com](mailto:ask@rainbowsireland.com)  
[www.rainbowsireland.ie](http://www.rainbowsireland.ie)

Your own notes



Children's Health Ireland  
at Crumlin