



Precious Times

Palliative care for children with cancer – A handbook for parents

Haematology/Oncology Unit, Children's Health Ireland at Crumlin

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Haematology/Oncology Unit, Children's Health Ireland at Crumlin
Published: 2000, revised 2004, 2016, 2019, 2023

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 **Irish
Cancer
Society** 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.



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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 in 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 can be given at home.

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

The purpose of this booklet is to give you and your family information that will help you during this difficult and uncertain time. We hope it will help reduce some of the anxiety that you might now be feeling on hearing that a cure is no longer likely for your child's illness. It is a booklet 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 booklet 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 booklet and our service will be of some help.

The start of your palliative care journey...



Meeting the palliative care team

Referral to the palliative care team (PCT) may be prompted by a change in focus of care for your child. Your child's consultant will meet you and discuss this change in focus and the options that may be available. There may be treatments available to help slow down the progression of the disease, which may also help with managing symptoms.

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 in the weeks and months ahead. 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.

The philosophy of care is to hope for the best while preparing for the worst, so meeting the PCT in either Crumlin, Temple Street or St Luke's Hospital Radiation Oncology Centre (SLH) can happen alongside treatment. Involving the PCT acknowledges that your child's prognosis is uncertain while allowing for practical and emotional support to be offered to you and your child for as long as is needed.



About the palliative care team (PCT)

Palliative care includes end-of-life care, but end-of-life care is only a small part of what the palliative care team does. The PCT will likely be involved in your child's care for many months and will support you and your child in many ways. This includes managing symptoms, giving you emotional support and helping you to think about your wishes at this time and to make decisions about your child's care. The PCT includes a consultant in paediatric palliative medicine and clinical nurse specialists, but your child will always remain under the care of the primary team who have known you since your child's diagnosis. The PCT in Crumlin / Temple Street / SLH will support both you and them. The PCT also forms a link between the different people and teams who will care for your child. These include:

- **The hospital team**
- **Your child's local paediatrician**
- **Your GP**
- **A clinical nurse co-ordinator for children with life-limiting conditions (known as the CNC). The CNC is a link between hospital and community teams, working closely with your GP, community palliative care team (CPCT) and paediatric unit**
- **A public health nurse (PHN)**
- **The community palliative care team (CPCT) (See next page)**



About the community palliative care team (CPCT)

Each county has a community specialist palliative care team (CPCT). 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 who work with a consultant in palliative medicine. The team guides and supports you through your child's symptom management alongside your GP (family doctor), paediatrician and the team in your shared care centre.

Some CPCTs are larger than others and may include social workers, occupational therapists and physiotherapists.

How the teams work together

Your primary team will contact the GP to update them on the change in focus of care for your child and discuss the plan to involve the CPCT. It is likely your GP will have worked with the CPCT and CNC previously.

A palliative care clinical nurse specialist then contacts the CPCT 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.

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 PCT, as needed. If your child has attended a local shared care unit, they may also be involved.

How are we going to cope?

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 or in another place that is chosen by you. 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. 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, coping may be more manageable for you. 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 may also be wondering how long your child will live. 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 team will support you in talking about this.

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.



Managing symptoms



Managing symptoms

Before your child dies you may worry about what symptoms they may experience. You may have talked about some of the likely symptoms initially with your consultant haematologist/ oncologist and clinical nurse specialists. The consultant in paediatric palliative medicine and / or the CPCT may also have spoken to you about what to expect. 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 does happen.

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.

Pain

For many parents, their greatest fear is that their child may have uncontrollable pain before they die. Your child may experience pain during the palliative care phase of their illness. Your team will endeavour to manage your child's pain at all times.

When children complain of pain, they may need pain relief, such as morphine or other similar medicines. Some children have more than one type of pain and may therefore need more than one medication.

We acknowledge that you, as a parent, know your child best and we will work with you. 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.

Emotional pain

Pain may also be in the form of emotional pain. Emotional pain is very real and important to address. Acknowledging the emotional aspect of your child's pain allows you to offer them comfort, by providing space and time to talk through what their feelings and fears may be. There are supports available to you to help you navigate this time.

Questions you may have about pain

It is important to consider some issues that may help you to know if your child has 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 have pain do not want to be touched, or they may have pain when they move. This can apply from infants up to teenagers. The aim of pain relief 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 have 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 have pain may remain active as they can learn to tolerate their pain, but the pain can be there and be very real. You will become skilled at reading your child's non-verbal cues, such as frowning or grimacing. 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 are fearful of needles. We will always consider other ways of managing your child's pain. 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** (into the nose): Some pain medicines can be given in this way.
- **Buccal:** Some medicines are given inside the cheek pouch.
- **Through the Hickman line (Freddie):** If your child's Hickman line is still in place, it may be used to deliver pain medication. This will be discussed with you.
- **By feeding tube:** If your child has a feeding tube, such as an NG or PEG tube, this can be used to give medication.
- **Transdermal:** A sticky patch with medication, such as morphine, which is applied to the skin.
- **Under the skin (subcutaneously):** Some children will not be able to have their medicines in the ways described above as they come closer to end of life. In this case, a very thin line is inserted under the skin to allow medications to be given as needed. A second line may also be inserted to connect to a pump with an infusion for continuous delivery of medicines. Your specialist palliative care nurse will explain how this will work and prepare you and your child.

Q *Will my child need a morphine infusion?*

A A morphine infusion may be of great benefit if your child is unable to take morphine by mouth. It is a very useful form of pain relief. There are still some myths associated with morphine:

✘ 'Morphine affects a child's breathing'

Morphine helps to relieve the sensation of breathlessness and so can help significantly when your child is breathless or has an increased work of breathing.

✘ 'Children can get addicted to morphine'

As long as a child has pain and morphine is given for this reason, your child will not become addicted.

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

Some children are on morphine for many months and may continue to go to school, even if they are on large doses. The amount of morphine each child needs is very individual. The correct amount is the amount that eases their symptoms of pain or breathlessness.

✘ '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.

Breathlessness

There are times where your child may feel breathless if their disease starts to affect their lungs. There is medication, such as morphine and midazolam, to help manage this.

A small handheld battery-operated fan that can generate a breeze on their face can help to reduce the sensation of breathlessness. It also allows your child to feel more in control, if they are old enough to use it themselves. Relaxation techniques can also be very useful to help alleviate feelings of shortness of breath that your child may be experiencing. The reassurance you provide by your presence and remaining calm, is so important at this time.

You may wonder if oxygen is helpful when your child is breathless, but giving oxygen doesn't relieve this type of breathlessness.

Nausea and vomiting

Some children have a problem with feeling sick (nausea) or vomiting. It is important to discover the most likely cause, as treatment will depend on this. For example, feeling anxious or worried can result in your child feeling nauseated. Taking time to allow them the space and opportunity to talk may help alleviate these symptoms. The use of a fan or fresh air may help to ease some of these sensations, as can the use of breathing techniques or distraction methods. There are supports available to you to help you with this. Nausea and vomiting are more common in children with brain tumours.

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 a combination of drugs may be needed to treat your child's nausea or vomiting.

Loss of appetite and weight

It can be very distressing for you 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 - the body's way of showing that it has less need for the energy previously needed from food. It is acceptable for your child to only eat or drink what gives them comfort rather than nourishment at this time.

Unless your child currently has a feeding (nasogastric) tube in place, it is not necessary to insert one. Your CPCT will be happy to discuss any aspect of this with you.

Constipation

When nearing end of life, your child's bodily systems may begin to slow down resulting in constipation. For some children this may lead to nausea, vomiting, tummy discomfort or lethargy resulting in your child not feeling like eating or drinking. If your child starts taking regular morphine, it is advisable to also start taking a regular laxative.

Regardless of how little your child is eating, a regular bowel motion may provide relief from some of their symptoms. Ask your nurse specialist for advice if you have any questions or concerns about your child's bowel motions.



Seizures

Some children may develop seizures as part of their disease. For example, seizures can happen with some types of brain tumours. If your child has previously had seizures, it is more likely for them to develop them again during this time.

Your nurse specialist will support you to manage a seizure at home. They will discuss this with you and tell you if your child is at risk and how to deal with the seizure.

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 these symptoms may occur. It depends on the part of the brain that is involved.

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 GP or on-call doctor.

Seeing your child have a seizure for the first time can be very upsetting. 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 died.

Infection

If your child has an infection, for example, a chest infection, your GP may suggest an oral antibiotic that your child can take at home. The aim is to manage any infections at home, to avoid your child going to hospital. If you have concerns about managing an infection at home, talk to your CPCT.

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. 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 haematologist / oncologist 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 with 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.



Bleeding

There are some circumstances when your child may be more likely to have a bleed. Your primary team or CPCT will discuss the likelihood of this happening with you and how to manage if this happens.

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

Bleeding is usually painless, however, it can be distressing for you to see. 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. Remaining with your child and reassuring them while being calm in this situation is so important.

Difficulty passing urine

Sometimes children may have difficulty passing urine for various reasons. It is very common that your child may pass less urine or may stop passing urine as their bodily functions slow down. 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 should contact your GP or specialist palliative care nurse. It is important to establish what is happening. Some children stop producing urine as part of the dying process.



Steroids

Steroids are often very helpful in the earlier stages of illness, but at this stage the side-effects may outweigh the benefits. For example, 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, pain-relieving medications 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.

If steroids are prescribed, then using for a very short period of time, e.g. days, is most advisable. You will probably be advised to give them no later than 2pm in the day so as not to interfere with sleep.

Complementary therapies

Complementary therapies are health-related therapies that complement conventional medicine. Therapies that may be provided are hand and foot reflexology, Indian head massage, visualisation and breathing techniques, mindfulness, progressive relaxation, use of aromatherapy oils and aromatherapy massage.

These therapies can support patients to manage symptoms, reduce anxiety, stress and distress and help families to cope. Complementary therapy creates a space that allows a deep connection with the therapist, where open dialogue is encouraged. It offers a key support by establishing a positive relationship in a non-threatening way, so that the patient feels they have permission to confide in the therapist. This supportive non-clinical relationship with the therapist can be extremely valuable to patients and their families.

Complementary therapy is a core support for patients and their families while on treatment and is central in the *National Model of Care for Psycho-Oncology Services for Children, Adolescents, Young Adults and their families in Ireland 2023*.

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.



What might happen as your child nears the end of their life?

Many parents wonder about the changes that may happen as their child approaches death. They want to be prepared for this. 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:

- Sleeping for longer periods of time, during the day as well as at night: As your child nears the end of their life, 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
- Weakness (they may need help to move around)
- Restlessness / confusion
- 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

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.

Questions you may have

Q *How long does my child have?*

A 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, if that is where you choose to be. In some areas, your specialist palliative care nurse can arrange for a nurse to be with you overnight if this would be helpful. This nursing service is provided by the Irish Cancer Society. Ask your GP or CPCT if the service is available in your area.

Pastoral care

Pastoral care plays an important role in supporting parents and families whose children are receiving palliative care. Pastoral care is provided by chaplains and caters to different religious and spiritual backgrounds. All families – those of different faiths and those of no faith – can receive comfort and support.

Pastoral care offers understanding and comfort to families who struggle with profound emotional, spiritual and existential questions. The pastoral caregivers will be fully present and sensitive to your family's needs. Pastoral care provides a safe, peaceful space where you will be seen, heard and valued and where you can express your fears, hopes and grief without judgement.

Through rituals, prayers or simply a listening ear, pastoral caregivers help families find some peace amidst the storm of a life-limiting illness. They bridge the gap between medical teams and families, providing care to support physical, emotional and spiritual wellbeing.

In the darkest moments, when words fall short, pastoral care shines as a beacon of support, affirming that no family walks this journey alone.



You and your family



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.

You know your child best, but what is happening now is uncharted waters for you all. There is always support available to you to help you – please reach out to your medical social worker or CPCT.

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 fearful 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. Try to be as honest as you feel you can be. Your child may have questions that you do not have the answers to or find difficult to respond to, and that is all right.

Most children want to protect their parents and may feel upset 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 any stage if they want to.

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. Try not to worry – 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.

The 6 Es for talking with your child*

Establish

Talk to your medical team to establish how they will answer your child's questions about death.

Engage

Look for signs that your child wants to talk or has questions. Engage with them when you feel the time is right for them.

Explore

Ask questions about what your child already knows, how they are feeling and what they want to know.

Explain

Give age-appropriate information to answer what the child wants to know or to address their fears.

Empathise

Be present with your child with their feelings. Cry with them and reassure them that you are there.

Encourage

Reassure your child that you and others will be there if they want to talk again or need help with anything.

**Based on Beale et al. (2006)*

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 (CPCT NURSE SPECIALIST)

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. But don't be afraid to use words such as death or dying. Though you may feel they are bleak words to use, they are less likely to lead to confusion or misunderstandings. Try 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.

Just like adults, children need information about what is happening (appropriate to their age and level of understanding). They also need the opportunity to ask questions and express their fears. If children are not prepared for the loss of a sibling, they may make up their own version of what could happen, which may be more frightening for them.

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.

Brothers and sisters 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 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.

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. 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.

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. 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 as 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 you and your child's wishes are for this precious time. 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.

Special events

You may want your child to make their First Holy Communion, Confirmation or to participate in other special events earlier than initially hoped for. You may find it helpful to explore this with your school, priest or religious leader. 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.

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.

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

Family and friends will want to support you during this time. This may result in more people in your home than you are comfortable with. Consider asking a family member or trusted friend 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

Creating memories, such as hand clay prints, as a keepsake for you as a family may be something that you would like to consider. This is available at your home or in the hospital before you go home.

If your child has already been referred to LauraLynn hospice, the creative arts team can come to your home to do some memory making with your child – and siblings if they wish to be involved. Parents tell us it is a special time of great sharing, often framed with moments of fun and laughter.



When your child dies...



Some questions you may have

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

A Although your child is at home, sometimes it is not possible to be there at the very moment when they pass away. This can happen and do not feel guilty about this. Instead be reassured about all the love and care you have showered on your child throughout their life and illness.

If your child dies during the night, you may have had a night nurse present to support you. They will respect your wishes to have uninterrupted precious time with your child if this is what you want. They can remove any medical devices at this time if you wish. When you are ready, you may also contact your GP and CPCT to come to check and examine your child.

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. The team caring for your child will respect your traditions and support you.



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

A This is an individual decision and all families have different wishes. It may be helpful to discuss this with your CPCT and your chosen funeral director to consider how best to meet your wishes. Some families may decide that their child stays at home for a night or more. A lot of families find this couple of days extremely useful in helping them begin to 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 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. Your funeral director will provide support and direction at this time.

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.

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.

Your child may also have shared particular wishes with you before they died. 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. Siblings often want to be involved in the funeral service and may have special wishes, tributes and contributions to make to the service. Being included in what is happening can nurture children's self-esteem and resilience. Prepare them also for what to expect at the funeral.



The following points may help you gather your thoughts. If you have your own cultural or religious traditions relating to death, you may need to make special arrangements and some of the points below may not apply to your situation.

- Talk to your funeral director about the types and colours of coffins available. Some parents choose a white coffin for a child. The funeral director 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.
- 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. 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, Meath (water cremation) and Belfast.

Dublin

Dardistown Crematorium

Tel: 01 842 4677

Email: dardistown@dctrust.ie

Glasnevin Crematorium

Tel: 01 882 6500

Email: glasnevin@dctrust.ie

Mount Jerome Crematorium

Tel: 01 497 1269

Email: info@mountjerome.ie

Newlands Cross Crematorium

Tel: 01 459 2288

Email: newlandscross@dctrust.ie

Cavan

Lakelands Funeral Home and Crematorium

Tel: 049 436 2200

Mobile: 086 2458489

Email: info@lakelandscrematorium.ie

Cork

The Island Crematorium

Tel: 021 486 4000

Email: info@islandcrematorium.ie

Clare

Shannon Crematorium

Tel: 065 671 3088

Mobile: 087 176 0001

Email:

info@shannoncrematorium.com

Meath

Pure Reflections Resomation

(water cremation)

Tel: 01 969 6990

Email: info@purereflections.ie

Belfast

Rose Lawn Crematorium

Tel: 048 904 48342

Removal to the crematorium may be direct from home or can follow a funeral service in a church or other place of worship. A service is also held in the crematorium. The ashes will be available in an urn some time after 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/or 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 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 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 '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. It is important to remember that children may not express their grief through words, but what they are experiencing is often reflected in their behaviour. With grief, children often regress and act younger than their age. Your child will benefit from being held and having more cuddles. Bedwetting and physical outbursts are other symptoms of grief that you may notice.

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 may be 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 or 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. Children may fear dying themselves or worry about something 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; they 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 gathering memories together.
- Make a memory box/jar to store things that hold special meaning for you about the person who has died.
- 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 GP, 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 seek more attention.

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 funeral directors' costs can vary. It is worthwhile considering two or three different companies before making your choice. The Department of Social Protection/ Intreo office may be able to help with some of the costs. This allowance is means tested so the amount given will vary. There may also be charitable assistance available to help with funeral costs. Your medical social worker will support you around this.

Registering the death

As a parent or legal guardian, you must 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. 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 once or twice a year. This can take place online or 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 inter-denominational (for all faiths) and held at a venue outside the hospital. You will receive an invitation to these events.

The bereavement service is completely voluntary and its aim is to support both you and your family at the time of death and in the months following.



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 them. 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 booklet aims only at guiding you, your family and your child at a time that is very traumatic and bewildering. It is not a booklet 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 booklet and our service will be of some help.

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



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

The Barretstown Bereavement Programme
www.barretstown.org

The Irish Childhood Bereavement Network
www.childhoodbereavement.ie

Irish Hospice Foundation
Tel: 01 679 3188
Email: info@hospicefoundation.ie
www.hospicefoundation.ie

Irish Cancer Society
Support Line Freephone: 1800 200 700
Email: supportline@irishcancer.ie
www.cancer.ie

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

Barnardos Children's Bereavement Service
Tel: 01 473 2110
Email: info@barnardos.ie
www.barnardos.ie

Rainbows Ireland
(Bereavement Group Support for Children)
Tel: 01 473 4175
Email: ask@rainbowsireland.com
www.rainbowsireland.ie



Books that you may find useful

Young children

When Someone Has A Very Serious Illness (1996)

Marge Heegaard, Woodland Press

Ida, Always (2016)

Caron Levis & Charles Santoso, Antheneum Books, New York

The Invisible String (2018)

Patrice Karst, Little Brown and Company, New York

The Memory Tree (2013)

Britta Teckentrup, Orchard Books, UK

The Memory Box – A Book About Grief (2017)

Joanna Rowland & Thea Baker, Sparkhouse Family, USA

Badger's Parting Gifts (2019)

Susan Varley, London: Andersen Press Ltd.

Water Bugs and Dragonflies – Explaining Death to Children (2004)

Doris Stickney, Pilgrim Press

Remembering My Brother (1996)

Ginny Perkins, A&C Black Ltd

On the Wings of a Butterfly, A Story about Life and Death (1992)

Marilyn Maple, Parenting Press

Goodbye Mog (2003)

Judith Kerr, Harper Collins Children's Books

When Dinosaurs Die; a guide to understanding death (2016)

Laurie Krasny Brown & Marc Brown Little, Brown Young Readers US

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Margot Sunderland and Nicky Armstrong, Routledge

Websites and mobile apps

[Headspace](#)

[Child Bereavement UK](#)


[GriefSteps](#)



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Children's Health Ireland
at Crumlin