precious times

a handbook on palliative care for parents of children with cancer

ONCOLOGY UNIT, OUR LADY’S HOSPITAL FOR SICK CHILDREN, CRUMLIN
Precious Times

Palliative care for children with cancer -
A handbook for Parents.

Oncology Unit, Our Lady’s Hospital for Sick Children, Crumlin
© Copyright 2004, Our Lady’s Hospital for Sick Children

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 Oncology Unit, Our Lady’s Hospital for Sick Children, Crumlin, Dublin 12.
It has been re-edited by Vicky Fourie (Social Worker) and Jane Garland (Liaison Nurse), along with both their teams. First published 2000, second edition published 2004.

Published by the Irish Cancer Society,
the national charity for cancer care in Ireland.

Acknowledgement

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

Introduction 2

THE START OF YOUR PALIATIVE CARE JOURNEY
Talking with your child about death and dying 4
Questions that may be on your mind 6
Managing symptoms 8
Brothers and sisters 20
Coping with the changes 22
Special events 24
Visitors 25

WHEN YOUR CHILD DIES
Some questions you may have 27
Planning your child’s funeral 29
Coping with your other children 33
Children’s grief 35
Guidelines on childrens understanding of death 40
The siblings charter 42
Practical matters after your child has died 43
Bereavement support service from the staff on St. John’s ward 45
Coping with the days and nights ahead 47
Books which you may find useful 50
Bereavement services / Organisations offering support 53
INTRODUCTION

The purpose of this book is to give you and your family information, which will hopefully help you during this difficult time of palliative care. It is hoped that the book will reduce some of the desperation that you might now be feeling on hearing that there is no further active medical treatment for your child’s disease. 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”.

The term Palliative Care is used to describe supportive care and treatment that is given to alleviate symptoms, but with the knowledge that it will not lead to a cure. Palliative care 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 end stage may have come as a total shock to you, or you may have been the one to identify it. Either way, the past few days have probably been the worst ever. At this moment you are most likely feeling shocked and devastated. Your abilities and strengths as a parent will hopefully be supported by us and by this book. Questions may arise in your mind, seeming almost too terrible to ask, therefore some of these will be addressed gently in this text.

It can be difficult to put some issues that are sensitive on paper. So the book is divided clearly into different sections, for your convenience. It may be that you will only be able to read some sections of this book at present. You may not be quite ready for it all yet, thus your Liaison Nurse and Social Worker are available to discuss any of the issues with you when you feel the time is right.

Your child is very important to us. We hope this book and our service will be of some help. For convenience throughout this book the dying child will be referred to as being male and the health professionals will be referred to as being female.
The Start of your Palliative Care Journey......
TALKING WITH YOUR CHILD ABOUT DEATH AND DYING

Many parents are very unsure how best to talk with their child about his condition 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 therefore any points that we might suggest are written with this in mind.

A strong desire to protect your child from the knowledge of his condition is a very common reaction on the part of many parents. This is often based on the belief that your child, with the knowledge, would become miserable and unable to enjoy what time he has left. However, as it is likely that your child knew everything about his cancer diagnosis and treatment up to now, he may find it strange and very worrying if that openness stops suddenly. Your child will quickly learn not to ask questions if he is not given some realistic explanation for the changes that are now happening.

Most children too, want to protect their parents and may feel guilty about the upheaval they are causing them and their family due to their illness. Because of this many 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 him a simple explanation of the recent change. He needs to know that his cancer has come back. It is also important to tell him that he will be receiving his medical care at home from now on. It may well be that this explanation will satisfy him for now. However he will need to know that he can ask questions, at a later stage, if he so wishes. Do let your child know that he has done his best and that he is not responsible for the return of the illness, because this is something he may secretly fear.

Some children do 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 it. 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, based on their child’s comments and expressions, that their child had some understanding of what was happening. You may have precious opportunities to share feelings with him without directly mentioning death and dying. We would encourage you to create openness with your child so that he can share if he so chooses.

If you feel at times unable to cope with such chats it is perfectly understandable and normal. However it is important not to deny what your child may be saying about his condition. Do not give him very unrealistic expectations that he will be better soon. While you may not feel able to talk with your child about all his fears and worries, there may be others he will talk to and open up to. Indeed he may feel at times that he does not want to burden you. Do try to give your child opportunities to talk with other trusted adults. Your Social Worker and Liaison 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.”
QUESTIONS THAT MAY BE ON YOUR MIND

Q. How are we going to cope?

A. Your Liaison Nurse and Social Worker will help you in planning the care your child will need now as most of this care can take place at home. It is important that your local Hospice Nurse meets you and your family fairly soon. Introducing this Hospice Home Care Nurse to you and your family early makes it easier for you all to get to know each other. Thus when the time comes that you need her more, a relationship will have developed. However some families find this first introduction upsetting.

Once the decision to begin palliative care is made, a meeting is held between your Liaison Nurse, Family Doctor, Hospice Home Care Nurse and Public Health Nurse. The purpose of this meeting is to identify likely symptoms that may occur and plan the treatment your child will now require. The Liaison Nurse will usually visit you following the meeting with a nurse from the local home care hospice team. They will explain their roles and discuss whatever you wish to know at this time. They will agree a visiting plan to suit you for the duration of your child’s palliative care.

We will always try to prepare you for things that might happen leading up to your child’s death. (There is a further section in the book regarding pain and symptom management). If you know what to expect and what to do when something happens, 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 while their child is well. The timing of these discussions is important - feel free to let your Liaison Nurse know if you want to talk about likely symptoms at present or at a later date.

“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 and different. The duration of your child’s life may depend on the type of cancer he has. Some children will die within a week or two and some will live for many months. It is unlikely that anything will happen suddenly. Most children die over a period of days and their families are expecting it. Your Hospice 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 that first notice changes. We will have told you what to look out for. It is usual that you will be expecting his 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. There is rarely any medical reason that would warrant your child being in hospital. Everything that would be done for your child in the hospital can be done at home.

“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 he is likely to develop in the palliative care phase. You may have talked about some of the likely symptoms initially with your Consultant and Liaison Nurse in Crumlin and later with your Family Doctor, Hospice Nurse, Public Health Nurse or Liaison Nurse again. Symptoms may be anticipated that never actually occur, however we feel it is important to discuss all the possibilities. If you have information regarding what is likely to happen and know what to do, the situation may be more manageable and less frightening should it become a reality.

“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 he dies. Pain is a reality for many children on palliative care; however the majority of pains are very well controlled with the use of appropriate medications.

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 ensuring 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, therefore we will obviously listen to you and your child for guidance in helping to control the pain.

When children complain of pain, initially they may only require something mild like paracetamol or codeine, but many children will need to start on morphine at some stage. It is important to consider some issues that may help you to know if your child is in pain and what to do if he is. 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 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 admit that he has pain?

A. Many children are aware that their admission of pain can generate much anxiety within the family and it brings with it a realisation for themselves and others that they are not getting better. Also fear of having to take more medication may lead them to hide their pain from you. 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 assess if your child has pain. It is 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 all right for you to ask that your child does not get an injection, if it is suggested. (Some children will still have their hickman line in and this can be used by the team to administer medication) Other routes that work very well are:
(a) **by mouth** - a choice of tablets, liquid or granules is available for most medicines.

(b) **rectally** - almost all tablets that are given by mouth can be given rectally. This route can be a very good option, especially for younger children.

(c) **under the skin** - if your child cannot swallow tablets, if the rectal route is not an option and if he doesn’t have a hickman line, it is possible to place a very small butterfly needle under his skin for administering medications. This needle is tiny and not at all like a cannula. The most commonly used site for the butterfly needle is the chest. The majority of children do not have a problem with this butterfly as it is very small. Emla cream can be used to numb the site before insertion. The butterfly is attached to a line and then onto a tiny syringe pump. This pump does not stop you from lifting or holding your child. The butterfly needle usually stays in for a few days. The Home Care Nurse or public health nurse will change the medication in the pump’s syringe.

(d) **through the hickman line** - if your child’s hickman line is still in place it may be used. This will be discussed with you.

**Q. Will my child need morphine?**

**A.** Many children on palliative care need morphine to control their pain. Some children will be sleepy for 1-2 days when they first start on morphine. This is only temporary and is unlikely to be an issue with further dose increases. Occasionally some children have mild hallucinations that are also temporary. Morphine will cause constipation. All children will need to start on a laxative when they commence morphine, as prevention is always better than treating. Morphine can provide great pain relief for your child, however there are still some myths about morphine which need to be discussed.

Exploring these “Myths about Morphine” will help you to understand how morphine really works:
* "Morphine affects a child's breathing!"
Morphine does not significantly affect the breathing pattern. In fact children who have breathing problems can get relief if on morphine, as it helps to relieve the sensation of breathlessness.

* "Children can get addicted to morphine!"
As long as a child has pain and morphine is given for this reason the child will not get addicted. As drug addiction is a topical issue and a taboo for many teenagers your child may need reassurance about.

* "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 attend school even if they are on large doses.

* "Morphine will bring the end nearer!"
Many people believe that morphine will bring the end nearer but this is not correct. Sometimes it is necessary to increase the dose of morphine as the child’s condition deteriorates, therefore it can seem as though the morphine is speeding up the dying process but that is never the case. When morphine needs to be started it certainly 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 the 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 their bodies’ natural way to gently wind down. Blood counts are not checked routinely, as these can produce more anxiety and present dilemmas about possible transfusions.

As your child becomes more and more anaemic the sleeping periods may become longer and they 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 may remain 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 him.

Blood transfusions are not given routinely and are only considered with caution. If however your child has a good quality of life except for the fact that he is very tired, do discuss it with the team. It is possible that a transfusion could then be helpful.

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 are 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 if really necessary. Sometimes it can take a combination of drugs to treat your child’s vomiting. The rectal route can be used effectively if appropriate for your child.
4. Constipation

All children on morphine or codeine will get constipated unless they take regular laxatives. Regardless of how little your child is eating he should be having regular bowel movements. If your child would normally have 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 be complaints of tummy pains, nausea and vomiting and sometimes diarrhoea (caused by overflow). Do 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 he may have difficulty with absorption. This is a natural process. It is important not to put pressure on your child to eat or drink if he is not able. Excess fluid can cause breathing difficulties nearer to the time of dying. Treatments such as starting nasogastric (n.g.) feeding or giving intravenous (i.v.) fluids, are avoided as they can be very difficult for the child and it is felt that they go against his 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 oral antibiotic. If your child finds it too difficult to take the oral antibiotic discuss it with your Family Doctor or your Home Care Nurse. I.V. antibiotics are avoided if possible as they necessitate your child being admitted to his local hospital, which 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 present in different ways. They may result in changed behaviour, altered breathing, jerking movements of the limbs, with possible loss of consciousness and incontinence. Preparing you for what could happen can ease the fear and help you cope in the event of your child having one. 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 there is a history of the child having had one in the past. Your Liaison Nurse will discuss this with you and tell you if your child is at risk and if so how to deal with the seizure.

If a seizure occurs, cushion your child’s head and turn him on his side until he recovers. It is unlikely to last more than three to four minutes. If the seizure lasts longer, it may be necessary to give stesolid, the rectal form of valium. Your team will have prepared you for this.

Observing 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 following the seizure. They may have little memory of the event subsequently. If, however, the seizure continues for more than five to ten minutes, phone your Family Doctor.
8. Bleeding

Children who are anaemic and have a low platelet count, may not be at a significant risk of bleeding, as the two low counts accommodate each other. Your child may have a bleed at some stage. If bleeding has been an issue in the past it may continue to be a concern.

“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 the child that the bleeding will stop. If the bleed can be controlled by outside pressure, like a nosebleed, continue to put pressure on the bleeding spot until the bleeding is controlled.

You may notice that there is blood in your child’s urine, stool or vomit. Just let your Family Doctor or Home Care Nurse know when you are talking to them next. Platelets are rarely given as they last for such a short time and have to be given in your local hospital.

9. Difficulty passing urine

Sometimes children are unable to pass urine. Their bladders become distended, which can be very uncomfortable. If your child has not urinated for some time (usually 24-48 hrs) and is unsettled, you need to contact your Doctor or Home Care Nurse. It is important to establish what is happening. Some children stop producing urine as part of the dying process.

If it is noted that the child has a full bladder, the first step is to encourage your child to sit on the toilet (if able). 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 in to the bladder to relieve retention. This may be left in or taken out immediately. This tube can be
inserted at home by your Nurse or Doctor and although a little uncomfortable can be done very easily and quickly. We would like to reassure you however that catheters are rarely needed.

10. **Physical changes**
Many parents wonder about the changes that occur in the child just before he dies. 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 at varying points 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 with them. He may not even be aware of these changes.

**Steroids**

Steroids have already been mentioned when we discussed nausea and vomiting. While they may have been a very useful group of drugs to use at an earlier stage of your child’s illness, at this point steroids are avoided if at all possible due to potential harmful side effects they may produce (tummy upset, mood swings and weight gain). Many children old enough to understand say that they find these side effects very difficult and 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. There are often effective alternatives to steroids however which are equally effective in controlling symptoms and result in fewer distressing side effects. As your child’s comfort and quality of life is our priority, these will be considered and used in preference where possible.
example pain killers such as codeine or morphine may be used to control headaches instead. There are also a variety of very effective medications available to control nausea and vomiting.

Occasionally steroids may be suggested to help improve your child’s appetite or general feeling of well being. Whilst they work this way in adults, in our experience with children this is rarely helpful and therefore not recommended. However, 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 deemed 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 a drug called prednisolone rather than dexamethasone and suggest that it should be given in the morning only to avoid restless nights.
Complementary therapies

There are a variety of complimentary therapies available. We respect that you may continue to look for any possible cure and explore other avenues for your child. Please feel free to discuss any therapy that you are considering. We will have an open mind and will try to guide you as best we can. In the alleviating of discomfort or anxiety, some parents have found aspects of alternative therapies helpful, for example massage therapy. However, we do feel that you should take care when a person promises you or your child a cure. This may raise hopes, when such promises are very unlikely to be kept.

If you are considering other treatments, it is important to consider the physical and emotional demands these may place on your child when his stamina and emotional coping may be limited, for instance travelling long distances. Some alternative therapies include specific activities or special diets for your child which he may find difficult to manage, and yet feel guilty if he cannot manage to sustain the alternative therapy. At a time when your family is under a lot of pressure, the commitment of some alternative therapies can demand a lot from parents and siblings; physically, emotionally and in terms of practical resources. Careful consideration can help in making your decision as well as discussion with a knowledgeable person. Asking your child what they think of an alternative therapy is also important in helping your child feel in control of what happens to them.

Only some forms of these therapies may be appropriate and helpful for your child. Reflexology, aromatherapy, music therapy, relaxation techniques / guided imagery, spiritual healing and distraction therapy have been used effectively and have given comfort to children and families. Although such therapies do not provide the “cure” many Families have reported a sense of empowerment, improved coping and improved quality of life when using such therapies.

“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.”
**BROTHERS AND SISTERS**

It can be hard to focus upon your other children at this difficult time. However, it is important to include them as much as possible now and thus reduce regrets later on. Brothers and sisters do require some information about what is happening based upon their age and level of understanding. Do try to spend a little time with each of your children daily if possible. Discuss with them that care will be given at home now, not in the hospital and 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 brother.

*“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 his illness returning, nor for any symptoms, as they may have their own hidden worries in this regard. It may be helpful if you explain your sick child’s behaviour towards them in terms of his symptoms. For example your child may have some pain, be irritable or want peace and quiet. Your other children need to know that their being around is not causing these symptoms, but that they are caused by the illness. Where possible encourage all your children to help in the care of their brother for example bringing him drinks, reading to him, etc. This will ensure they feel involved and important.

As your child comes closer to death it is important to prepare his brothers and sisters as much as possible, given their ages and personalities. Ideally older children should be told that their brother is dying. Establishing, for example, whether they wish to be present at the time of the death, or if they wish to be awakened should the death takes place during the night, can be helpful. They need their own opportunities to say good-bye in their own individual way. With younger children it may be wise to wait until the last few days before telling them of what lies ahead, 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 attend school, both as a distraction and as a way of coping with the weight of what’s going on. However do 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 his brothers, sisters or friends about his 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 peers 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 them 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 such a dark cloud hangs over him. 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 yourself. All you can do is your best, as you have done already all through your child’s treatment. Some parents choose to stay working full time in the early days of palliative care, this can help to maintain some routine. Other parents choose to spend more time at home. Be flexible when making these plans, taking 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 his period of palliative care. Many children are very keen to return to school and in most cases this is possible, even for short periods. Your school booklet may be helpful again at this time. Do discuss this, with the school principal and class teacher, prior to your child’s return. As many children may have previously experienced restrictions due to chemotherapy, they especially treasure this new freedom, despite being difficult for parents. Your child may wish to continue spending time with friends and being out and about for as long as he is able. It is important to allow your child have as much freedom as he wishes 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

It may be that you and your child may want him to make his First Holy Communion, Confirmation or to partake in other special events early. You can join with a local school group or have a private ceremony and most priests and clergymen are very accommodating. Some families take a video of the day. However planning such important events may trigger some questions from your child. You will need to give some thought to how you will explain your plans to him.

Many well-meaning people may encourage you to head off on a major trip for example to Lourdes or Disney Land. Some families have felt 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. He 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 not to exclude brothers and sisters in these plans. If you are thinking of a long journey do discuss the implications and practicalities of it with your Liaison 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 so do let people know clearly if you would prefer them not to call as often. Your child may need you to protect him from visitors he may find intimidating or tiring. He may feel he is on view, with people staring at him and talking over him. Your 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 have used an answering machine to filter their calls and have found it useful. 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. It is your home so do continue to decide what is best for you all.
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 alerting relations and friends of the death. 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 can you may wish to wash and dress your child yourself or you might want the nurse or a relative to either help you or do it for you. Putting a nappy or pad on him can help. Choosing what your child wears is entirely up to you. Many children wear their favourite dress or tracksuit. 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 remains in place. You do not need to call the undertaker 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 later).

Most families decide that their child should stay on his bed or on the sofa after he has died. Many parents also like to sleep with or lie beside their child. Some want to take a photograph or cut a lock of his hair to keep. It is also possible to take a print of your child’s hand or foot, as a keepsake. This is something in which other children in your family can participate. Pressing your child’s foot or hand onto an inkpad or using children’s paints enables you to take a print that you can keep forever.

Your Family Doctor will usually see your child after he has died, when you are ready to call her. She will sign the death certificate. More details about this will be covered later in the book.
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 wish. A lot of families find this couple of days extremely useful in helping them come to terms with the finality of what has actually happened. It is vital that close family can take time, on their own, with your child. This may be particularly important for brothers and sisters, if they wish and can 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, he can then spend two or three days with you, in your 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 him. 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 and 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. Different cultures and faiths have their own traditions relating to death. We appreciate that special arrangements for different religions must be made, thus 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, as 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.

Choices you can consider:

* Most families choose to keep their child at home in the family setting. It is not necessary to put your child into his coffin, while he is at home. Your child can lie on the sofa, where it is easier to hold, touch, sit or lie beside him. This will make it much easier for your other children to spend time with him, 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.

* In selecting your child’s coffin you may need to choose a size bigger than your child’s height. Some parents choose a white coffin for a child but you can discuss what types and colours are available with your undertaker before making your decision.

* It is not usual or necessary for a child to remain in a church or funeral directors over night. Most children are taken directly from home to the Church for their funeral service and burial 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. Undertakers offer the service but it is usually not necessary. In some circumstances however it may be required especially if there will be a long delay between your child’s death and the funeral. Early discussions with your hospice home care nurse or liaison nurse will help prepare you for such decisions. Embalming often warrants taking the child away from your home and this may give rise to a delay before your child can be brought
home again. It is ok to take your child in your car to the embalmers and can wait in a waiting room if you wish to do so. Some undertakers can offer an embalming procedure that can be done at home. You may decide not to have your child embalmed and your child can stay at home for 2-3 days if the heating is off in the room and there is good ventilation.

**Burial**

In selecting your child’s grave you may wish to consider purchasing a family grave where you yourself can be buried. 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 an undertaker, check whether he has access to the cemetary you prefer. Many families who had gone to the graveyard, before the funeral, felt 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 & Belfast:*

- Glasnevin Crematorium Ph. 01 - 8305211
- Mount Jerome Crematorium Ph.01 - 4971269
- Newlands Cross Crematorium Ph.01 - 4592288
- Rose Lawn Crematorium, Belfast. Ph.028 - 90448342

Removal to the crematorium may be direct from home or can follow the funeral service in the local church. A service is 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 bury them in a family grave or distribute them in a favourite place. If you choose the latter you might note that some family members like to retain some ashes in a smaller urn placing them in a grave or in Glasnevin, thus ensuring that they still have a specific place to go to pray or remember, perhaps at anniversaries or birthdays. Alternatively they can be placed in the Columbarium Wall of Remembrance in Glasnevin. Here the urn is placed behind a stone bearing your child’s name. There is also a communal plot in the Garden of Remembrance in Glasnevin.

**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. Talk over, as a family, the music, readings, offerings, gifts, poems, photos you would like at the service. Let your priest, minister or religious advisor 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 type out and photocopy 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**

The following section refers mainly to brothers and sisters, but contains some advice that might help you in deciding how to help any children that were important in your sick 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 are. Try not to have particular expectations of how your children will grieve or should grieve, but rather offer encouragement and support to help them grieve in their own individual 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 as their brother died, but if not, break the sad news openly and simply and explain in a way which each 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 trigger unnecessary fears.

It will also help sometime over this early period to talk with the children about what will happen and what to expect at the funeral service. Offering 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. Facilitate them in being involved and included as they wish and as their age permits.
Selecting a Key Adult

You, as parents, may feel very stressed and burdened at this time and for this reason it may be helpful if an adult, perhaps a close relative or friend, takes the other children ‘under her wing’. She may offer much needed support and create the opportunity to share feelings and answer questions. She can also reassure the children and help them understand that it is all right for Mammy and Daddy to cry and be sad. Discourage her, however, 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 brother is an opportunity that is very special. 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 initially you might feel this will be too frightening for your children, the experience of other families more than demonstrates the value of this approach. Your children are more likely to draw comfort and have fewer regrets by being involved and it 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, which may well have to do with their own relationship with the child who has died. One child may have been especially close to him and thus is losing a best friend and brother. Alternatively if there was conflict between the children, your child may now feel guilt or blame. 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 brother. 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 occur when they have happy carefree feelings or when they remember having been jealous of their brother. They may also feel guilty that they have survived and inadequate that they cannot make you happy. Also many children secretly worry that somehow they 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 brother for dying and leaving them. Many children may also feel anger towards their parents, God, or the hospital, for letting their brother 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 hinder 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 e.g. 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, e.g. bed wetting in an older child. Also parents have found that they become over protective of their well children.

“We found that we were over aware of our other children’s health after Anna’s death and would bring them to the G.P. 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 lonely days ahead:

* Regardless of age, good communication helps. It is helpful to be open and honest and share feelings. You, as parents, being open about your sorrow and tears, will give your children the message that they too are permitted to be sad. They will need encouragement not 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 too and that they are special to you as well.

* 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 nightly.

* 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. They may wish to refer to the school booklet. 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 sad memories 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 Liaison Nurse.

* 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, maybe 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 his 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 brother dies, though 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 brother to come home, as if he 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 e.g. 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. Tummy aches and pains may present occasionally.
Adolescents
12 Years -

This group is very aware of the raw reality of death. Emotions may be hidden and not talked about. They are very aware of peer and friend’s reactions. Moodiness, arguments, detachment, ‘don’t care’ attitude, feelings of depression and a changed attitude to school work may be noticed. Keeping the door open for communication and offering reassurance can help. Some 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 and sister as much as you do, but that doesn’t mean we’re not thinking of him or her.

* 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 Our Lady’s Hospital, Crumlin 1998.
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 be of help in making phone calls or keeping appointments on your behalf. They may also cancel allowances and clinic appointments as necessary for you when your child has died.

Financial

Funerals can be very expensive and undertaker’s costs can vary. It is worthwhile considering two or three different companies before making your choice. If you are on a low income, your community welfare officer in your local Health Centre may be able to help with some of the costs. This is a means tested allowance so the amount given will vary accordingly.

Registering the Death

Your child’s death must be registered with the Registrar of Births, Deaths and Marriages in the district where the death occurred. If your child dies in hospital, the hospital will register the death in their local district office. The hospital can advise you on whom to contact. If your child dies at home, your own GP who attended him will provide you with a medical certificate. You or a relative can then take this certificate to the District Registrar’s Office, where the death will be registered in the presence of the Registrar. It is important that you register the death. You are then provided with a death certificate and there is a fee payable for this document. This cannot be done over the phone or by letter.
**Bereavement Grant**

If you are an employee paying PRSI contributions or in receipt of certain Social Welfare payments and meet the necessary requirements, you can make an application to the Department of Social Welfare for this €635.00 grant. The Bereavement Grant is paid by cheque to the mother or father, or next of kin, and only one Grant is payable.

**Application forms** are available at the local office and must be returned with a death certificate and funeral bill within 12 months of the date of death. The address is Department of Social Community and Family Affairs, Ballinalee Road, Longford, Tel: 043-45211.

**Cancelling Allowances**

You will need to notify the Children’s Allowance section 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 receiving a Domiciliary Care Allowance, or using a Medical Card or a Long-Term Illness Card you can notify your local Health Board Office.

If you have been claiming Social Welfare Benefits 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 ON ST. JOHN’S WARD

A member of staff involved with the care of you and your child, will make phone contact in the days after his death. Other members of the team will ring over the following days, usually your social worker, Liaison Nurse, and possibly your consultant.

Unfortunately we are not in a position to send a representative to every funeral, due to the distances involved in travelling to attend funerals. Rather than turn up to some funerals and not others, we have reluctantly adopted a policy of not attending any funerals.

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 Liaison Nurse will be the principal contacts in this service. At this particular time any contact you make with us is voluntary on your part, and at your pace. As there are a few different parts to the Bereavement Support Service we have found that some families take up some parts of the service, some families use none, and some use all parts of the Service.

In the immediate month your Social Worker will be in contact to offer support over the phone. Thereafter you can opt for what level of continued phone contact you would like to maintain with your social worker.

Your Social Worker can also send you some reading material on Bereavement, including reading material and workbooks for siblings that are also bereaved.

Some parents like to return to the hospital to meet with the consultant and other staff members. This usually occurs months or sometimes even years later and can be arranged by the Social Worker for a time that suits you. This can prove to be a valuable visit as you may have unanswered questions, which you would now like to ask. It can also provide a chance for you to meet some of the ward staff you knew over the period of your child’s illness.
The Social Work Team also endeavour to run events that provide Group Support for parents from St. John’s whose child has died. This is usually in the form of a Bereavement Day. Sometimes this has been a Bereavement Day just for parents, sometimes there is a simultaneous Day for Siblings as well. These days take place in a venue outside the hospital. Usually there is a speaker and then we break up into groups. Many parents find it very helpful to meet others who have also lost their child from cancer.

There is also an annual Remembrance Service, which is interdenominational, held in the Hospital Chapel. On this day there is music, prayers and a candle light procession. If you are unable to attend, a candle can be lit in memory of your child. You will automatically receive an invitation to these events.

The Chapel contains the Book of Remembrance, which is maintained by the Patient Support Service within the Hospital. Usually about six months after your child has died they will write inviting you to enter your child’s name in the Book of Remembrance. To mark your child’s entry into the book they run their own Remembrance Service, where you are invited to attend a similar service to that mentioned above.

In providing this 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, between 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. Occasionally parents speak about seeing, smelling or feeling the presence of their child. You may have 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 can be so strong that it can be frightening and overwhelming. Medication may be offered at this point but this may not be helpful in coping with your grief.

Failure to think clearly, lack of concentration, memory loss and being prone to accidents are common features, but 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, after being previously very busy. If you feel you have too much time on your hands, it may be useful to plan to do specific things, e.g. 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 when this happens there are regrets afterwards. Experience and research suggest that it is best not to make any major long term decisions in the first twelve months following bereavement. Most people find that their views and opinions can frequently change during this period. Well meaning friends and relatives may pressurise you to choose a headstone and send out memorial cards shortly after your child’s death. Ensure you undertake 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 may not prove to be the case because everyone grieves in different ways and at a different pace. Accepting this and giving each other time and space can often be necessary.

“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 may 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. Often for you to start the conversation is all that is needed.
You may feel under pressure to ‘return to normal’. This feeling may come from yourself and from others. Don’t let this influence you too much, as you must decide what is most helpful for you, for example decisions regarding 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. Some parents find it helpful as it highlights that their feelings are normal. Some people decide to put off reading them 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 Social Worker and Liaison Nurse on St. John’s Ward and your local team will follow up on all issues that occur to you while 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


 Older Children / Adolescent


General Reading for Adults


RACHEL’S STORY. Published by Veritas and available from Veritas bookstores


Books on How To Help Children Through Bereavement


HEALING A TEENS GRIEVING HEART, 100 PRACTICAL IDEAS FOR FAMILY, FRIENDS AND CAREGIVERS (2001) Alan D. Wolfet, Companion Press, USA.

OUT OF PRINT SECTION

These books are no longer available from bookshops as they are out of print, however, they may still be accessible through libraries. As some of them have been recommended in the past by parents we felt it important to include them

Children/Teens:


ADULTS:

5 1/2 x 3, THE SHORT LIFE AND DEATH OF JOE BUFFALO STUART (1990)

A PART OF OURSELVES, LAMENT FOR LIVES THAT ENDED TOO SOON (1997)
Ed. Siobhan Parkinson, A. & A. Farmer, Dublin

BEREAVEMENT SERVICES AND ORGANISATIONS OFFERING SUPPORT

The following services may be helpful to you:

- Social work departments of hospitals and hospices
- Local health board services
- Family doctor / Public Health Nurse / Home Care Nurse
- Voluntary bereavement services
- Private counsellors and psychotherapists
- Local psychiatric services
- A voluntary organisation with which you may have been involved during your child’s illness
- Bereavement support services attached to your church/parish/community

If you feel the need to make contact with a local Bereavement service your Social Worker or Liaison Nurse from St. Johns, or indeed your Home Care Nurse from the Hospice, will be happy to point you in the right direction.

Some of the following addresses may also be relevant to your needs:

HEBER (Umbrella Organisation for Hospice Bereavement Groups)
c/o Ann Keating, Heber Secretary
Social Work Department
Harold’s Cross Hospital
Harold’s Cross
Co. Dublin
IRISH HOSPICE FOUNDATION
32 Nassau Street
Dublin 2.
Tel: 01 - 6793188
THE IRISH CANCER SOCIETY
5 Northumberland Road
Dublin 4
Tel: 01-2310500
Email: info@irishcancer.ie
Freephone Helpline: 1800 200 700
www.cancer.ie

THE BEREAVEMENT COUNSELLING SERVICE,
(Adult, Children and Family Bereavement Counselling)
Various Locations: Greater Dublin Area, Bray, Carlow and Newbridge
Dublin Street
Baldoyle
Dublin 13
Tel: 01 - 8391766
e-mail: bereavement@eircom.net
Web site: www.bereavementireland.org

SOLAS (Bereavement Counselling for Children)
Barnardo’s
Christchurch Square
Dublin 8.
Tel: 01 - 4732110 (Mon-Fri, 10am – 12 noon)

RAINBOWS IRELAND Ltd (Bereavement Group Support for Children)
National Office
Loreto Centre
Crumlin Road
Dublin 12
Tel: 01-4734175
Email: rainbows@eircom.net