

# Palliative Care for Children with Cancer – A Guide For Parents



Queensland  
Government

# PALLIATIVE CARE FOR CHILDREN WITH CANCER – A GUIDE FOR PARENTS



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# FOREWORD

For the majority of children with cancer, the aim of treatment is cure. Some childhood cancers however are very difficult to cure. Approximately 30% of children with cancer will not be cured of their disease. For these children and their families the direction of care slowly changes from aiming for cure, to controlling symptoms caused by the disease and allowing the child and family to enjoy the remaining time that they have.

Families usually express a deep desire to spend this time at home surrounded by their family and friends. Home may be hundreds of kilometres from the oncology unit where they have been for much of the child's treatment. The desire to return home is also often met with great anxiety about who will care for the child at home and how the family will cope as the child becomes more unwell.

The level of care and support that families are given while their child is receiving palliative care, greatly impacts upon how families cope. For this reason the Oncology Unit at RCH Brisbane initiated a palliative care project in 1998. The aim of this project was to increase knowledge of paediatric palliative care throughout Queensland enabling a more consistent approach to the management of symptoms and support for families.

An important component of this project was to gain insights into families' experiences of caring for a child with progressive cancer. Nineteen parents participated in the project and shared positive and negative aspects of their child's palliative care.

Parents identified areas where they felt more support was required. All parents requested written information on what to expect as their child's illness progressed and suggestions on how they could better care for their child. Access to 24 - hour phone support from staff with experience in paediatric oncology palliative care was also highlighted.

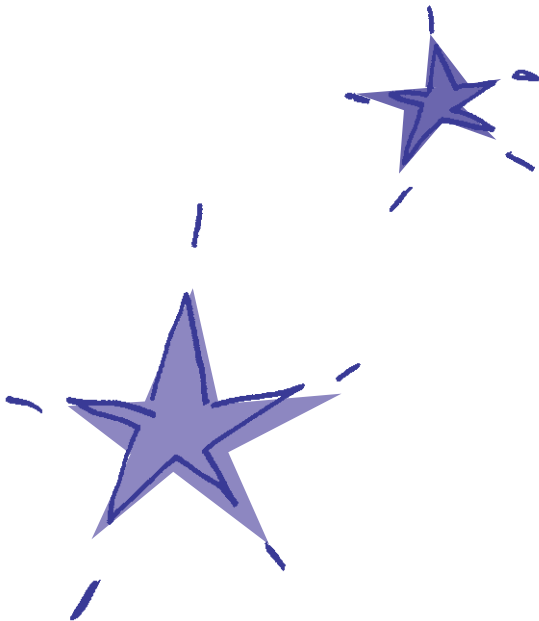
The recommendations from this research have gradually been implemented and this Guide has evolved from the initial research. It is hoped that the information will be helpful in addressing some of the difficult emotional and practical issues that are associated with caring for a dying child, as well as providing accurate information about what you can expect as your child's disease progresses. The areas covered in the book address questions commonly asked by parents. The information given stems from our professional experience but more importantly from sharing the palliative care journeys of many families.

You may wish to read the entire book or choose to read sections as the need arises. It is our aim that the book will complement the support and advice that you receive from health professionals caring for your child and is an additional resource to which you can refer as required.

# ACKNOWLEDGEMENTS

There are approximately 100 children diagnosed with cancer each year at the Royal Children's Hospital (RCH) Brisbane. Children are referred from throughout Queensland, northern New South Wales and occasionally the Northern Territory and Pacific Islands. For some of these children cure will not be possible and they will eventually require palliative care. Families generally request for this care to be delivered in their home town, enabling them to be close to friends and family.

To assist with the transition to home, staff from the Oncology Unit RCH Brisbane have previously written a guide for health professionals. The current book has been written specifically for parents, outlining issues related to palliative care.



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# INTRODUCTION

## WHAT IS PALLIATIVE CARE?

Paediatric palliative care is a concept of care for children with a progressive life limiting illness, and their families. The care involves the coordinated services of doctors, nurses, social workers, therapists and teachers. The aim of palliative care is to give children the best quality of life possible despite progression of the disease.

The appropriate management of symptoms and provision of emotional, spiritual and social support to the child, family, school and community is essential. The care is provided where possible in the environment of the child and family's choice. Paediatric palliative care also includes grief and bereavement support for the child, family, school and community, during the palliative care time and following the child's death.<sup>1</sup>

## WHEN DOES PALLIATIVE CARE BEGIN?

For many cancers of childhood, there is no definite point at which the direction of treatment changes from cure to palliative. Each child's illness and the response to treatment directs this transition. For some children there may be a long curative approach to their illness with a relatively short palliative period. For other children it may be known from the time of diagnosis that treatment will be palliative, and this may last several months or even years.

When all realistic attempts for a cure have been tried, your child's oncologist will discuss with you and your child (if appropriate) what choices and options are available. You may require time to consider the option of palliative care. Support and guidance will also be offered from social workers, nursing staff and other members of the team. It is usually a very difficult transition for a family to make and each family will respond differently. Initially, the

change to palliative care may start with a decision to no longer use aggressive chemotherapy and over time further discussion about the place of care and the extent of supportive care can occur. Your hope for a cure may slowly be changing towards a different type of hope – a hope for quality time with your child and hope for a peaceful and dignified death.

## WHAT ABOUT ALTERNATIVE TREATMENTS?

When a child's cancer continues to return despite using best practice treatments, many parents accept that cure is not possible. For some parents, however, the desire for cure is so strong that more alternative options are sometimes explored. When considering using alternative treatments it is important to consider if the treatments will interfere with the amount of quality time you have left with your child. Some alternative treatments require the child to undertake procedures or drink preparations that are unpleasant and this could result in conflict with your child. Other treatments can be very expensive with no proven benefit.

Some natural therapies may however contribute to your child's general health, and these may be better referred to as complementary therapies. If you or your child wish to use alternative or complementary therapies it is important to discuss this with your child's oncologist or oncology pharmacist to ensure that the preparations are compatible with medications your child may be taking.





## WHERE WILL MY CHILD BE CARED FOR?

Often in the early stages of palliative care, children appear quite well and may have very few symptoms. They are likely to be at home, attending school and participating in family activities. Most children express a wish to have fewer trips to hospital. As the child's disease progresses and symptoms develop, closer follow up with the oncology team will be needed. Depending upon where home is, this review may be via telephone, videoconference, home visits or hospital visits. At times, admission to hospital for assessment and management of difficult symptoms or for respite care may be needed.

As your child's disease progresses, it is important for the family to decide whether the final days will be spent at home or in hospital. Your child may have a definite opinion about where they wish to be cared for. Some families presume that their child will have to die in hospital, and for some this is preferred. However, with appropriate resources, many families will prefer to have their child at home. This will require support from your oncologist, paediatrician, local doctor, oncology clinical nurse consultant (CNC) and community nurses. When needed, daily home visits by community nurses can be arranged. The nurses are able to provide emotional support and assist parents with caring for their child.

You may find that your thoughts fluctuate between the idea of hospital and home care. This is understandable and you are able to change your mind during your child's illness. There will always be

a bed available in hospital, if at any time you feel hospital care is more appropriate. If your child is in hospital, where possible they will be nursed in a single room. This can be transformed into a bedroom by bringing in doonas, pillows, favourite toys, photos and other special items from home.

Wherever you choose, you will have access to 24-hour advice and support from health professionals with experience in paediatric palliative care. Hospital and community based health professionals will work together with you to care for your child.

# WHO WILL HELP ME CARE FOR MY CHILD?

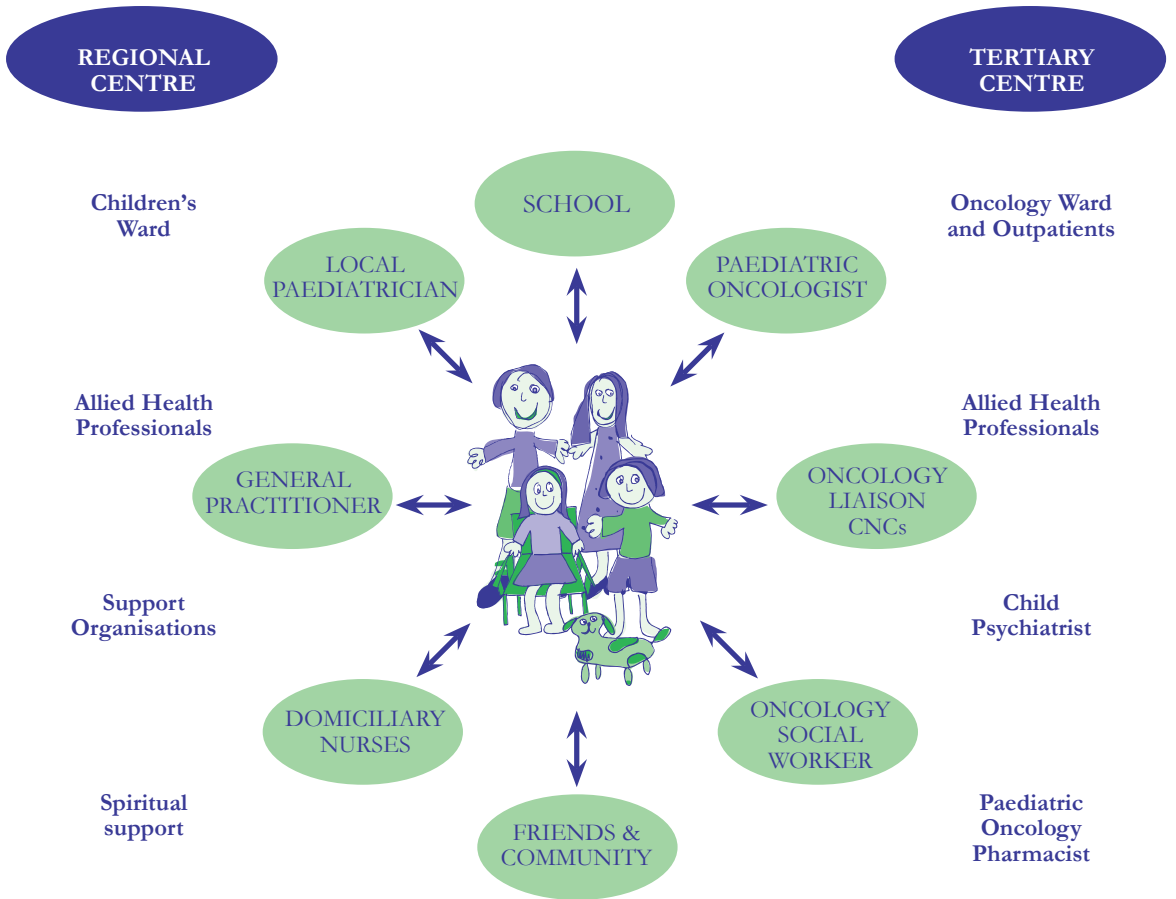
Professional staff who may be involved in your child's care include doctors, nurses, social workers, pharmacists, occupational therapists, physiotherapists and teachers. As there may be many people involved, it is important to have one health professional as the key person coordinating your child's care. This gives you a person to contact as new issues and problems arise. For example, in Brisbane the oncology CNC will be the key person. For families who live outside Brisbane then it may be more appropriate for the paediatrician, local doctor, hospital or community nurse to take on this role.

Often problems or concerns arise after hours or on weekends when it is more difficult to obtain help. It is for this reason that the Royal Children's Oncology Unit provides an after hours phone support service for all RCH oncology palliative care families. A toll free 1800 phone number has been established for the *Paediatric Oncology Palliative Care Outreach Nursing Service*. The service is for parents and health professionals. Experienced paediatric oncology nurses provide the 24-hour outreach nursing service with support from the paediatric oncologist on call. Other oncology units often provide a similar service.

Friends and family may also be very anxious to help. They may wish to offer practical assistance such as baby sitting, shopping, ironing and cooking meals. Having this type of help may give you more time to spend with the family and allow you some time to rest. You could also consider electing a relative or friend to act as a "family spokesperson" to deal with some of the repeated enquires about how things are going. Do not feel that you are obliged to accept all offers of help or invitations to visit you at home. This is your time with your child and it is your choice as to how you spend this time.<sup>2</sup>

Who looks after us at home?

# WHO WILL HELP ME CARE FOR MY CHILD?



**Figure 1** - Model of family centred paediatric palliative care  
 (Adapted from Thompson A, et al<sup>3</sup>)

# **FAMILY CONCERNS**

## HOW WILL WE COPE?

Each family has its own way of coping and this is influenced by life experiences, resources, supports and the nature of their child's illness. It is important to realise that you do not have to manage everything on your own. The oncology social workers and local social workers are available to assist your family to cope with the varied emotional responses you may be feeling. They will also provide practical assistance related to employment and financial concerns. It is important that you talk with your social worker to alleviate unnecessary stress and to arrange suitable local supports for the family.

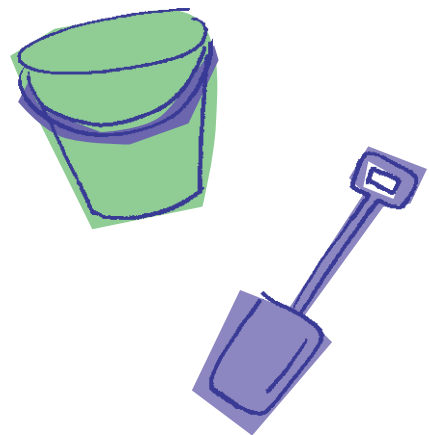
There is a wide range of feelings and emotions that are experienced during palliative care. These emotions may vary depending upon the circumstances surrounding them. It is normal to experience a number of different and even conflicting emotions including - anger, sadness, fear, guilt, blame and denial. There will also be moments of joy and happiness as quality experiences and special moments occur.

Individual family members will have different ways of responding and behaving. Some may resort to busy activities, which distract them from the progression of the child's illness. Others may become reflective, isolating themselves in private thought, and this may lead to misunderstandings and hurt feelings. It is important to understand that individuals need to be accepted even when their way of coping is not clearly understood by the rest of the family. <sup>2</sup>

Mothers and fathers may have very different coping strategies, therefore spending time with each other, doing enjoyable activities, and communicating your individual coping needs to each other is important.

Palliative care may last for some time, and not every moment needs to be spent with the sick child. A trusted friend, or relative may be prepared to stay with the sick child, to allow opportunities for you to spend time with each other and your other children.<sup>2</sup>

Some family members will find comfort in sharing feelings and fears with a trusted person. This person may be a friend, relative, minister, social worker, nurse or teacher. Others may be afraid of being overwhelmed by their feelings and choose not to express them. Both approaches need to be respected and protected by gentle responses.



## ISSUES FOR GRANDPARENTS

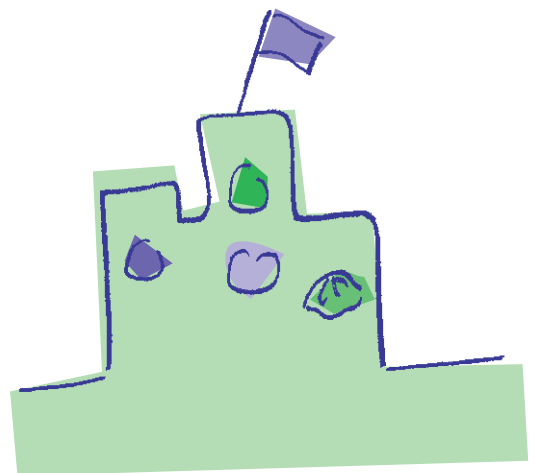
Grandparents may experience a range of unique feelings and thoughts during their grandchild's palliative care. It is difficult for any parent to understand and accept the death of their child and this difficulty also exists when grandparents try to make sense of the death of their child's child. Grandparents must cope with the added dimension

of seeing their child's grief. This can be very difficult and feelings of guilt are not uncommon. This guilt stems from the fact that normal assumptions about the natural lifecycle are being challenged. Grandparents may feel it is unfair that their grandchild will not have the same opportunities to experience different aspects of life.

## WHAT DO WE DO WITH THE TIME WE HAVE LEFT?

The amount of time a child has to live, after disease relapse or progression, is often difficult to predict. It may be weeks, months or many months. When told that their cancer can not be cured, some children have very specific requests as to how they wish to spend their time. For one child it may be staying away from the hospital, being at home and fishing as much as possible. For another it may be going on a special holiday with their family, or it may be continuing to attend school and spending time with their friends. If there are specific holidays or adventures that you wish to take, it is advisable to try to do these early in the child's palliative care to ensure that your child is well enough to enjoy them. If it is anticipated that medical care may be required while on holidays, this can be coordinated through your oncologist.

For most parents the focus at this time is ensuring their child is free of pain and distress, thereby providing the family with the opportunity to do whatever the child's health allows.

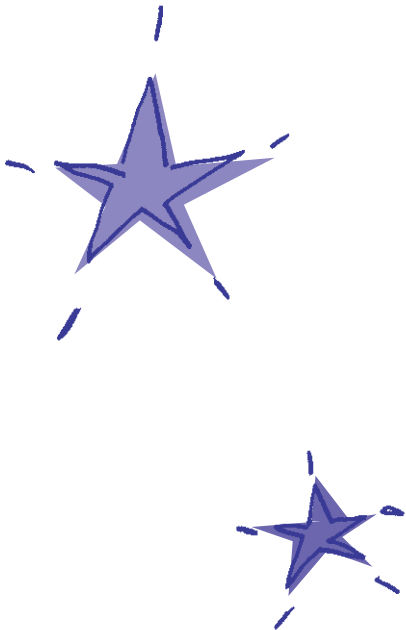


## WHAT DO WE TELL PEOPLE?

The decision about what to tell people and whom to tell differs for each family. Some families may choose to tell a small handful of close friends and family, so they are not overwhelmed by the response. Others will choose to tell the majority of their contacts and will welcome the community support this can bring.

The nature of your relationships will help guide you in this decision. If you are telling someone you know well, you may choose to tell them that your child is dying and share with them some of your experiences and feelings. There may be times when you need to tell people whom you may not be close to. At these times you may choose to say that your child is very unwell and that you are taking things one day at a time. The important thing to remember is that it is your choice as to whom you choose to share information with.

## SPIRITUAL/RELIGIOUS ISSUES



Many families find that when attempting to come to terms with the inevitability that their child will die, spiritual and religious issues can become more significant. Families' religious/ spiritual beliefs vary considerably. Some families find comfort and meaning from their beliefs. Some discover that their beliefs are greatly challenged and for other families religious or spiritual beliefs have no bearing.

It may be helpful to discuss these matters with your social worker or nurse who can facilitate linking with chaplains, ministers or counsellors to assist in exploring some of these questions and concerns.

## HOW DO WE TELL THE CHILDREN?

The following guidelines and suggestions, for talking with children during palliative care are intended for all children in the family. The sick child, as well as brothers and sisters, need help to make sense of what is happening and how this impacts on them physically and emotionally. This assistance is best given from the people they love and trust – you, their parents, and from carers with whom they have a trusting relationship.

### **What do children make of the palliative care experience?**

Children strive to make sense of their world, to gain a sense of mastery over it and to understand how they fit in to it. They do this by asking questions, listening to others and by watching how people react to life situations. There is no doubt that from their experiences and observations children in palliative care situations recognise when something serious is happening to them or their sibling. Alarm bells may sound for them by simply noting that Mum and Dad are having more meetings with the doctors, nurses and social workers, or when Mum and Dad look as though they have been crying. These observations can make children anxious and they will often want to make sense of what is happening and how it affects them.<sup>1</sup>

Sometimes parents want to protect their children from this sadness and may try to convince themselves that their children do not understand what is happening. Parents may feel that by giving limited information to their children they are protecting them. Children may engage in a similar strategy of protecting their parents. They do this by not talking about topics which they know will upset their parents. This shared protection can leave both children and their parents having similar concerns, yet being isolated from one another's support.<sup>1</sup>

While this shared protection is meant with the best intentions, it does not allow children the chance to develop an accurate understanding of what is going on in their lives. They are left uninformed, unprepared and at the mercy of their limited life experience and their often vivid imagination. They may completely misinterpret events around them. They may also come to the conclusion that they are in some sense to blame for what is going on, or that they are no longer loved by the family. These feelings of exclusion arise at the very time when children most need to feel included and loved.



## HOW DO WE TELL THE CHILDREN?

### What to tell the children?

It is important to understand that it is impossible NOT to communicate something to children. Every contact with them communicates something and every exclusion from contact tells them something else. Our tone of voice, gestures and body language, all send messages to children.<sup>1</sup>

With this in mind, good communication with children occurs within relationships where children feel included, respected and listened to. You may find it helpful if someone whom you and your child trusts and respects, is with you when you are talking about issues that you know may be upsetting. This person may be your child's oncologist, social worker or oncology CNC. Their knowledge and experience can provide you with support and reassurance. It also provides an opportunity for your children to ask questions of health professionals about issues that concern them. The information children are given needs to be honest, and explained in words that are appropriate for their age.

It is important to remember that children often have a limited "sad time". It is not uncommon for them to run out and play, or watch a video after they have been given sad information about themselves or their sibling. These responses are completely normal and children will ask more questions when they feel ready.

Some practical suggestions to guide communication with children are outlined below:

- Ask children what they understand is happening.
- Give information gradually over time rather than giving it in one large session. It is better to keep children informed of gradual developments or changes in the illness, than to give them all the information late, when the situation is more

serious. This then allows children time to adjust to what is happening.

- Answer the questions they have but don't overwhelm them with extra details.
- Keep language as simple as possible.
- Give the information repeatedly. Children generally need repeated explanations.
- Involve children in decision making as much as possible.
- Reassure children that the situation is not their fault and they have done nothing to cause it.
- Avoid "white lies" as they will break down a trusting relationship.
- Observe their play and behaviour for signs of distress.
- Use material that they are comfortable with (eg books, art, toys, story telling).
- Spend time creating memories by encouraging children to make a book about themselves including their favourite foods, clothes, friends, holidays, what makes them sad, angry etc. This can be an activity that the sick child can do with siblings or a friend and encourages expression of feelings.
- Don't be afraid to show how you feel to your children. It demonstrates to them that it is ok to express their own feelings and to cry if they want to.

This style of communication gives children the clear message that they will be kept informed of what is going on and it reassures them they are a valued part of the family and they will continue to be cared for.<sup>1</sup>

# WHAT DO CHILDREN UNDERSTAND OF DEATH?

It is difficult to clearly divide children's understanding of death into age groups. This is because children can have very different life experiences, such as having a life threatening illness, knowing a grandparent, friend or pet who has died, or having specific spiritual beliefs associated with death. These will all have an influence on their understanding of what death is. The following is a broad outline of children's understanding of death.<sup>3</sup>

Children of 2 years and younger understand "here" and "not here". They can sense loss but cannot comprehend death intellectually.

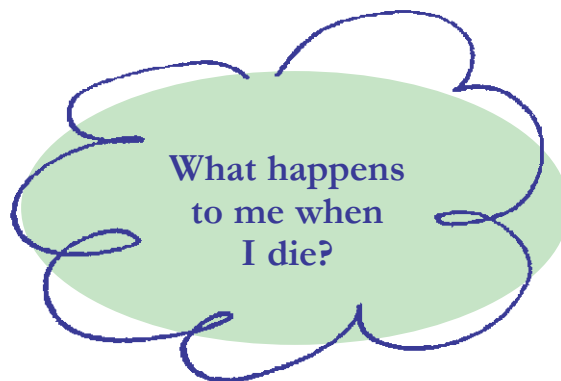
Children 3 to 5 years see death as a temporary state; death is a disappearance from which the deceased will soon return.

Children 6 to 10 years understand the reality of death and may be curious about funerals and cemeteries. They understand that death is forever, that there are a number of different causes, and that you can no longer do things when you die.

Children over the age of 11 perceive death as a permanent state in an adult way. They may look for the meaning of death.

Children with cancer and their siblings have had a greater level of contact with illness and may be aware of the death of children they have become friends with through hospital and camp programs. This may mean that at an even younger age, they have a greater understanding of what death is and what it means.

It is important, however, not to make assumptions of what you think your children's understanding of death is. You may be able to gain a better understanding of what they think death is and why it occurs by talking to them about people they have known who have died. There are some children's storybooks listed in the "Books" section of this Guide that may be helpful in introducing general discussions about death and dying.



## HOW DO WE MANAGE THEIR BEHAVIOUR?

There may be some changes in your children's behaviour throughout the palliative care period. Your sick child may experience feelings such as anger, fear, confusion, sadness and depression. These feelings may be in response to their illness and the limitations this places on them. It could also be due to specific medication they are taking. Some medications such as steroids can cause mood swings and behavioural changes.

It is important that you tell your child's doctor or nurse of any changes in behaviour. Your child's behavioural changes could also be related to the

illness, for example, a child may be irritable and withdrawn because of pain. The social workers and occupational therapist can also offer helpful suggestions to assist your child express emotions through play, art and music techniques. They may be able to do individual work with your child at home or in hospital.

Well siblings may also display behaviour that is unusual for them as they try to cope with their brother or sister's illness. The social workers can assist you to access counselling, which may help them in dealing with the emotional turmoil that may be occurring.

## ISSUES TO CONSIDER FOR TEENAGERS

Adolescence is a time of change when children are striving to become adults. The teenager experiencing palliative care will also have some very unique issues to deal with. They have a good practical understanding of death and may understand what impact this will have on them and their family. They also have a greater sense of the future and perhaps have already started to plan what their life may have looked like.

These issues can make the palliative care period for a teenager even more difficult than for a younger child. It is important that your teenager has the opportunity to express feelings, fears, regrets and hopes. As teenagers, they may have developed some close friendships and may feel more comfortable confiding in trusted friends. This may be difficult for you at times, as you may feel excluded from

their thoughts but these peer supports will assist your child during this time.

Another important aspect is the consideration that teenagers are striving for independence and acceptance of their adult status. It is important that an honest adult approach is adopted and that privacy is respected. It is important that teenagers are included in all decisions regarding their care, including informing them of any adverse effects of suggested treatments. This will allow them to make informed choices about their care.

## WHAT DO WE DO ABOUT SCHOOL?

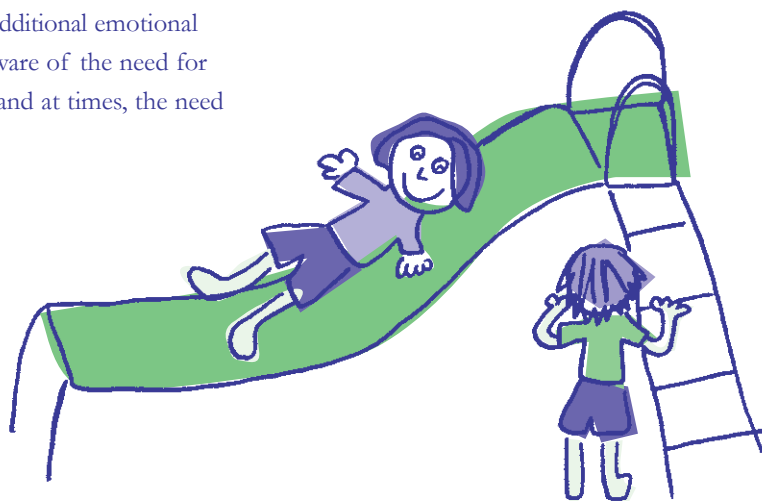
Apart from the family, school, preschool and kindergarten are generally the most significant networks in a child's life. Schools are important learning environments for children not only in academic terms but also in development of life skills. Schools are nurturers of children's social and emotional well being, and are places where important friendships are formed.<sup>1</sup>

It is important to consider the role you wish the school to play in your child's life during palliative care. It may be important to have the opportunity to maintain friendships with classmates and the opportunity to attend lessons and other enjoyable activities. This could mean attending school for favourite art lessons or coming at lunchtime to catch up with friends. If your child is not well enough to attend school, teachers often have suggestions on how friendships can still be maintained – friends visiting at home, classmates making a video or sending letters and e-mails.

It is also important that the siblings' teachers are aware of the extra stress they are dealing with. If their teacher is aware of what is happening at home, the school may be able to offer additional emotional support. They will also be aware of the need for days off school if required, and at times, the need

for additional time to complete assignments for example. A clear plan can also be set for getting messages to siblings quickly if needed.

Many families feel comfortable talking with the school on their own, especially if the family already has an open and supportive relationship with the school. If you would like assistance talking to the school, speak with the oncology social workers or oncology CNC. They can coordinate who the appropriate person is to help you with this. Often teachers welcome the opportunity to speak with health professionals, as they may have had little experience with children receiving palliative care. This can include a visit or telephone contact to the school to talk informally with the teachers on suggestions for supporting your children, their friends and the school community.



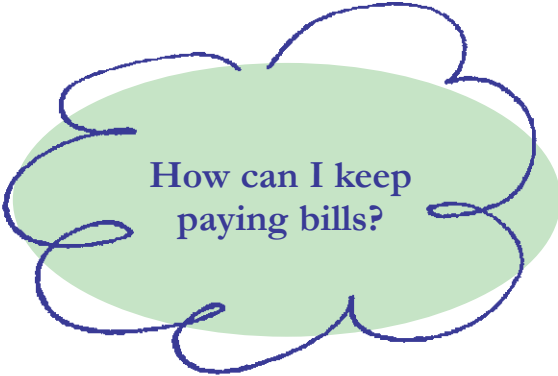
## HOW DO WE MANAGE FINANCIALLY?

While your child is receiving palliative care you may find it difficult to continue previous working arrangements, which subsequently may impact on your family income. This situation combined with a potential increase in expenses to maximise the quality of your child's life, can often create financial difficulties for some families. As your family's financial circumstances will be unique, it can be helpful to discuss any of these issues with your social worker, who can facilitate access to financial assistance.

In general the following options may be available:

- Income protection insurance claims
- Centrelink Sickness or Unemployment Benefits and Carer's Allowance
- Emergency financial assistance  
eg. bill payment or food vouchers
- Funeral assistance

Many families are reluctant to seek financial assistance, preferring to find solutions through their own support networks. However at this very difficult time it can be beneficial for the whole family to reduce practical stresses as much as possible, allowing you to focus on making the most of the remaining time. Your social worker will be able to assist you in this process.



**How can I keep  
paying bills?**

# **MANAGING DIFFERENT SYMPTOMS**

## WHAT IS SYMPTOM MANAGEMENT?

As the disease progresses, children may experience symptoms or problems related to either the illness or specific medications. The type and location of the cancer will generally determine the symptoms that children experience. The aim of symptom management is to identify the cause of the problem and to use appropriate treatment to alleviate any distress or discomfort.

The aim of this chapter is to provide an overview of the more common symptoms experienced by children with progressive cancers and how these symptoms are best managed. Your child's doctor and nurses will guide you as to the type of symptoms your child is likely to experience. It is important to contact the key person coordinating your child's care when any new symptoms arise. This will ensure prompt assessment and management.

## PAIN AND PAIN MANAGEMENT

A common fear for many parents is that their child will experience increasing pain. Children with cancer will experience pain, however, in most circumstances pain can be well controlled with proper assessment of the cause and with the use of correct medications and other treatments.

Children experience pain in the same way as adults but they sometimes find it difficult to describe the nature and severity of the pain. As a child's vocabulary and past life experiences are often limited, it is more difficult to obtain accurate descriptions of the pain. Any change in behaviour such as irritability, waking from sleep or being withdrawn, may indicate discomfort. Walking with a limp, not wanting to move, facial grimacing and holding an area that hurts may also indicate pain. Simply observing a child at play or at rest will give an indication of the level of pain.

### Causes of pain

The pain experienced by children with cancer is related to a number of causes. For children with leukaemia, bone pain often occurs and is caused by increased numbers of leukaemia cells causing pressure in the bone marrow space. This pain may be experienced as an aching pain in the legs, ankles, shoulder or arms. Children may also complain of headaches, abdominal pain or chest pain caused by pressure from specific tumours. Other causes of pain include infection, mouth ulcers and pain from procedures such as blood tests.

## The management of pain

The aims of pain management are to relieve pain at rest and during activity, and to ensure comfort during sleep with minimal side effects. The World Health Organisation (WHO), Cancer Pain Relief Program states that drug therapy is the mainstay of treatment and given the correct drug, dose and interval, pain relief is possible for most patients.<sup>4</sup>

Careful monitoring of the pain and response to treatment will ensure the medication can be adjusted if the pain changes. Parents play a very important role in their child's pain management by observing their child for longer periods of time. They also have a better understanding of any changes in their child's appearance or behaviour, which may indicate pain or discomfort. If you are concerned about your child's pain, contact the key person managing your child's care.

## Pain medications

The most convenient way to give pain medication is by mouth, in tablet or liquid form. The medication should be given regularly so there is continuous pain relief. Initially simple medications such as paracetamol will often be used. If this is not successful stronger medications will be introduced.

The pain experienced by children with progressive cancer usually requires stronger medications to relieve the pain. These are called opioids and include drugs such as codeine, morphine and fentanyl.

At times for a variety of reasons parents are reluctant for their child to start using morphine. They may think it is addictive, that it may mean that the end is near or that it will make their child confused and sleepy. These are all common concerns about morphine use, but if your child's doctor thinks morphine will relieve the pain, you will be given written information that will help to reduce your concerns.





### How is morphine given?

Morphine can be given in a variety of ways, including by mouth, by injection, via a drip and rectally. By mouth is preferred, as it is easily absorbed and tolerated by most children and can be given easily at home. Often children will commence on a morphine mixture or liquid that will give pain relief quickly and is given every 4 – 6 hours. When good pain relief from regular morphine mixture is achieved, a change to a longer acting morphine can then occur. The longer acting morphine comes in tablets, capsules, syrup or granules and is given once or twice a day. The morphine mixture is still used for any breakthrough pain, as it gives prompt pain relief.

You will find it helpful to keep a written daily record of the medications given for pain relief. This will also assist the doctors caring for your child to adjust the medication doses as required.

**It is very important that you contact staff as soon as your child experiences increasing pain. Do not wait until morning to contact someone, as your child's pain will then take longer to get under control.**

The doses of morphine can often be adjusted over the telephone and someone will keep in touch to ensure your child is comfortable.

If your child is unable to take morphine by mouth, it can be administered as an infusion through a small needle that is inserted just under the skin on the arm, leg or abdomen. The morphine is infused continuously through a small portable machine called a Graseby Pump. Community nurses can assist parents to use these pumps at home and they can refill the syringe each day.



## Side effects of Morphine

All preparations of morphine can have side effects. Constipation is the main problem.

**Laxatives should always be given whenever children are taking morphine.** Unlike other side effects, in particular nausea and drowsiness, tolerance to constipation does not occur. Nausea and vomiting may occur when first starting morphine and an anti sickness drug can be given. After administration of breakthrough doses of morphine it is not unusual for drowsiness to occur, but once a stable dose of morphine is achieved, this becomes less problematic. Itching can also occur and can be relieved with the use of an antihistamine.<sup>1</sup>

## How is Fentanyl given?

Fentanyl is another type of strong pain medication that is available in injection form or as a skin patch. In children it is most commonly used in the form of a patch that is applied to the skin every 3 days. The drug takes time to be absorbed through the skin and is therefore best suited for children whose pain is already controlled on morphine. Fentanyl patches are considered for children who have difficulty taking oral morphine or when there is difficulty in swallowing. The child needs to be on a specific and stable dose of morphine before being changed over to a fentanyl patch.<sup>5</sup>

## Other treatments for cancer pain

For some types of cancer pain chemotherapy or local radiation treatment may be suggested by your child's oncologist. These treatments can be given with pain medication and are often very effective in relieving pain caused by tumour pressure. The morphine dose can often be reduced following effective radiotherapy.

Some types of cancer pain are not very responsive to opioid drugs, particularly pain caused by compression of nerves. Other medications are likely to be more effective for this type of pain.

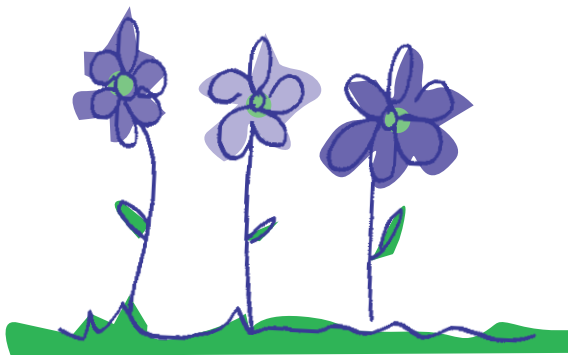
## COMPLEMENTARY THERAPIES

Complementary therapies are treatments that can be used alongside medical treatments to assist with relieving symptoms. There are a variety of complementary therapies that are helpful in relieving pain.

The use of physical therapies such as cold and warm packs, massage and electrical therapy with a TENS machine can all provide some relief. Cold and warm packs are readily available from the hospital or local chemist and can be used on areas of discomfort. Massage and touch are simple effective techniques that are soothing. There are a number of different massage techniques including foot, hand, head, back and shoulder massage. Using mild oils or lotions may make massage easier and more relaxing. The use of massage can also provide the opportunity to involve siblings in their brother or sister's care. Siblings will feel as though they are contributing and the massage can become a special time to share.

The use of a small TENS (Transcutaneous Electrical Nerve Stimulation) machine may be useful for muscle and nerve pain. It relieves pain by sending small electrical impulses through electrodes placed on the skin to nerve fibres and may block pain signals to the brain. The physiotherapist will be able to advise if your child would benefit from the use of TENS and can educate you on using the machine at home.

Encouraging children to participate in enjoyable activities such as playing with friends, watching videos or reading stories may also help to distract them from specific discomforts. Older children often benefit from learning relaxation techniques such as breathing exercises, meditation and guided imagery. These techniques may help to distract children from thinking about their pain and gives them a useful tool to help cope with stressful events. Occupational therapists and social workers will be able to help children learn and master these techniques.



## ORAL PROBLEMS

### Mouth Care

As a result of decreased immunity, poor oral intake and a general reluctance to do mouth care, children receiving palliative care may develop mouth problems. Regular mouth care, such as cleaning the teeth twice a day with a soft toothbrush and using anti bacterial mouthwashes can prevent many oral problems. Applying an anti-bacterial gel to disposable mouth swabs can clean the mouth, especially in babies and young children. Older children may also find this helpful.

### Dry Mouth

Dry mouth and lips are a common problem and can be caused by mouth breathing, dehydration, anxiety, drugs and infection. Simple measures such as sucking ice cream, ice cubes, frozen juices and drinks will moisten the mouth and relieve thirst. Chewing or sucking unsweetened pineapple pieces can also help clean the mouth. Regularly applying paraffin ointment or lip balms will help to keep lips moist and prevent cracked lips.

### Mouth ulcers

Mouth ulcers may occur if children are neutropenic or if infection is present. All mouth ulcers are painful. Small shallow mouth ulcers will often be relieved with simple analgesic mouthwash. Applying a topical anaesthetic gel on a cotton bud, particularly before meals, is also very effective at relieving discomfort.

The cold sore virus often causes larger ulcers and these can be very painful. They can also be present in the throat making it difficult for children to swallow. Cold sore antibiotics in addition to analgesic mouthwash are often needed. With severe ulceration and pain, morphine may be needed to relieve the pain.

### Mouth Bleeding

Children with a low platelet count are also susceptible to bleeding from their gums and mouth. Soft toothbrushes or mouth swabs should be used for mouth care. Applying cold compresses or ice to the bleeding area will often stop the bleeding. There is also specific medication that may help with mouth bleeding. For some children platelet transfusions may be appropriate. Discussion with the hospital staff will help identify the best treatment plan for this distressing problem.

## NAUSEA AND VOMITING

It is important to contact your child's doctor or nurses as soon as nausea or vomiting starts so treatment can be commenced promptly. Nausea and vomiting can occur for a number of reasons. The most common cause is related to the use of medications like morphine. Other causes of nausea and vomiting include – constipation, blockage of the bowel by tumour, infection, inflammation of the stomach and raised pressure within the brain.

## NAUSEA AND VOMITING cont.      CONSTIPATION

There are a number of drugs that work well in treating the different causes of vomiting and after your child's doctor has identified the probable cause medication will be given. If possible, as for pain relief, medications are given orally. Initially, this may be difficult if vomiting is severe. Treatment can then be given intravenously, subcutaneously or rectally, until the vomiting is under control.

If the cause of nausea and vomiting is constipation, treatment for this will relieve the problem. Raised pressure within the brain can cause vomiting and is often associated with headache. This is more common in children with brain tumours. Steroids such as dexamethasone will relieve these symptoms, along with medications that act on the vomiting control centre in the brain. If vomiting occurs as a result of blockage to the bowel, a nasogastric tube may be required to stop the vomiting and allow fluid to drain from the stomach.

In conjunction with medications some other suggestions may be helpful in reducing nausea and vomiting:

- Encourage small frequent meals rather than large meals
- Encourage bland foods such as crackers, noodles, pieces of apple etc
- Offer frozen juices in addition to fluids
- Try to avoid spicy or rich foods and avoid exposure to strong smells
- Encourage your child to sit up when eating to help with reflux

Constipation refers to difficulty, discomfort or delay in bowel motions, compared with what is normal for your child. For example if your child usually has a bowel movement every day, then it is important for you to contact their doctor or nurse if there has been no bowel movement after 3 days. Constipation is an extremely common problem and can contribute to abdominal pain, nausea and vomiting and overflow diarrhoea.

There are different types of laxatives and the type used will depend upon the cause of constipation and whether your child prefers tablet or liquid medication. Constipation can also be reduced by:

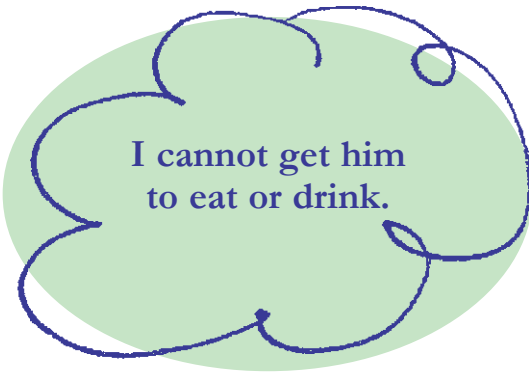
- encouraging your child to increase their fluid intake
- giving a daily glass of pear or prune juice
- eating liquorice
- adding high fibre foods, such as weetbix, fruit, wholemeal breads etc

**Remember that if your child is taking opioids such as morphine, a laxative should always be given, as opioids are the most common cause of constipation.**

If constipation can not be relieved by laxatives and diet then a suppository or small enema may be needed. This will usually clear the lower bowel, allowing for normal bowel patterns to be re-established. Once constipation is relieved, it is important to continue laxatives to prevent constipation from recurring.

## DIARRHOEA

It is important to notify your child's doctor or nurse if your child develops diarrhoea, as children can easily become dehydrated. They will assess what is causing the diarrhoea and implement the appropriate treatment. In some children, diarrhoea can be a sign of significant constipation requiring treatment. This is referred to as overflow diarrhoea. Simple measures such as stopping certain medications, withholding nasogastric feeds or a change in diet will often ease diarrhoea. In some cases, medications may be required to settle the diarrhoea. These drugs are generally well tolerated and very effective.



## WEIGHT LOSS AND FEEDING ISSUES

Significant weight loss is quite common in the later stages of palliative care and seeing your child lose weight can be very distressing. There are many reasons why weight loss occurs. Pain, nausea, mouth ulcers, constipation, reduced appetite, anxiety and depression all contribute to weight loss. Cancer itself, however, is the main cause for weight loss and all the mechanisms for this are unclear. As the disease progresses, your child's appetite will reduce significantly and it is best to offer small frequent meals as desired. It is quite common however for children to show very little interest in eating and they may refuse most meals.

There may come a time when your child can no longer tolerate oral fluids. A discussion regarding the possibility of commencing feeds or fluids in other forms may need to occur. These decisions are different for each child and are influenced by factors such as the progress of the disease and the effects of introducing additional fluids. Increasing feeds / fluids may worsen symptoms, especially vomiting and abdominal pain. Children can remain quite comfortable even when they are taking in very little food or liquid for a significant period of time.

# GASTROINTESTINAL SYMPTOMS

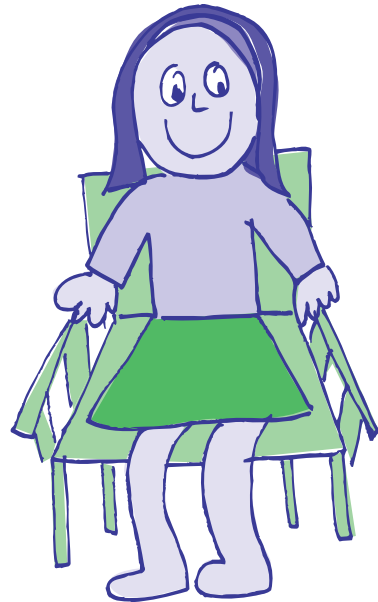
## WEIGHT GAIN

Some children require corticosteroid medication to help reduce symptoms such as headaches and vomiting, caused by pressure from brain tumours. A common side effect of steroids is retention of fluid in the tissues. This can give the child a swollen puffy face and is often referred to as a cushingoid appearance. Whenever possible steroids are used for short periods to try to limit these side effects.

Children are often very self-conscious about their change in appearance and may need help from the occupational therapists and social workers to adjust to these changes. It is also difficult for parents and other family members to see their child or sibling look different, as well as dealing with the physical restrictions caused by the illness.

## SECONDARY TUMOURS

With progression of the disease, some cancers spread to other organs including the liver, lungs and brain. If tumours invade bone and surrounding tissues lumps often develop under the skin. These secondary tumours are often seen in children with advanced neuroblastoma. The tumours may cause pain and regular morphine is often needed to relieve this pain. For some children, local radiotherapy may be considered in addition to regular pain medication. The radiation treatment is usually well tolerated and may also slow the growth of the tumours. These tumours can be distressing to see and parents may choose to cover these with clothing or hats.



## ANAEMIA

Anaemia occurs when there is a low level of the oxygen carrying pigment haemoglobin (Hb) in the blood and is related to a reduced production of red blood cells in the bone marrow. If anaemia is interfering with your child's activity level and causing tiredness, headache or irritability a blood transfusion may be required. Transfusions may be of benefit if a planned outing or activity is arranged. Blood transfusions generally need to be given in the hospital and the health professionals working with you will coordinate this.

As the illness progresses, activity levels are likely to reduce and the benefits of transfusion may be less. At this time, decisions regarding the value or benefit of continuing transfusions may need to be made. If the trip to hospital is becoming too difficult and there are no benefits then it is appropriate to stop blood transfusions.<sup>1</sup>

## BLEEDING

Children with disease in their bone marrow are also likely to have a low platelet count that may cause bleeding. Signs of bleeding caused by low platelets include bruising and petechiae (very small red or purple spots on the skin) nose bleeds, bleeding gums and dark bowel motions. It is important to notify your child's doctor or nurses when any bleeding occurs. If there is a bleeding episode, then applying gentle pressure to the bleeding area will usually slow the bleeding. The use of coloured towels and bedding to disguise the bleeding will help to reduce anxiety.

The appropriate treatment of bleeding is dependent upon the site of bleeding and the child's condition. A platelet transfusion may be appropriate for some situations, where other options may be considered for smaller bleeds.

For children who live in rural areas, it may be difficult to acquire platelets at very short notice. For these children, giving platelets routinely once or twice a week may help keep the platelet numbers up and often prevent bleeding episodes. The platelets can be ordered in advance and given at a time that suits the local hospital and family. As platelets can be transfused over a short period of time, it might sometimes be possible to administer platelets at home, if there are community nurses with suitable experience.



## BREATHLESSNESS

Breathlessness or difficulty with breathing is relatively common in children with progressive cancer. Children will naturally be anxious and distressed by this feeling. It is important to try and stay calm and offer simple measures to help reduce anxiety allowing easier breathing.

- Changing positions from lying to sitting can improve lung expansion
- Increasing air movement with a fan and improving ventilation in the room by opening windows is often helpful
- For older children encouraging deep breathing and breathing more slowly may also help
- Playing relaxing music may also reduce anxiety and assist the pattern of breathing

Breathlessness can occur for a number of reasons including – chest infection, blocked airways, tumours in the lungs and chest wall, pain, anaemia and pressure on the diaphragm from abdominal tumours. Some of the causes can be easy to treat. For example, a short course of antibiotics may be given to treat a chest infection, or pain medications will relieve breathlessness caused by pain. A blood transfusion may be appropriate if anaemia is causing shortness of breath.

For children who have tumours in their lungs, oxygen therapy may be helpful in relieving some of the unpleasant symptoms associated with a low level of oxygen in the blood. These include headache, dizziness, nausea, daytime sleepiness and confusion. If oxygen is required, oxygen concentrators can be organised for home.

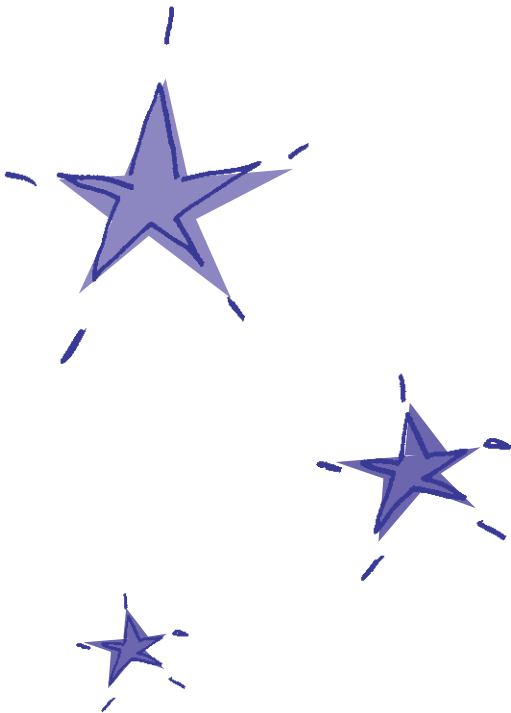
Oxygen in portable cylinders can also be supplied for outings to the park, shops etc. In some cases oxygen will only be needed occasionally, for more physical activities such as walking or bathing. If no benefit from oxygen is noted, or the use of oxygen upsets the child, it should not be used.

## COUGH

Many of the conditions that cause breathlessness will also produce a cough. Cough results from irritation to the upper or lower respiratory tract, the pleura or diaphragm. This can sometimes be managed by avoiding irritants, giving antihistamines for post-nasal drip and antibiotics if required. Simple cough linctus will also soothe the throat and reduce an irritant dry cough. Bronchospasm or wheezing also contributes to cough and medications through a puffer with a spacer maybe helpful. For children with a persistent dry cough, medications such as morphine may be needed to suppress the cough. Occasionally morphine via a nebuliser may be helpful.<sup>1</sup>

## MUSCLE SPASMS

Muscle spasms can occur as a result of immobility, pain, or cramps. When children become less active and spend more time in bed, the chance of muscle spasms increases. Simple measures such as changing position in bed and encouraging them to move around or have short walks as tolerated will help reduce muscle spasms. There are also medications that can be used to minimise or stop muscle spasms. Muscle twitching can sometimes occur in children who are receiving morphine and is usually managed by adjusting the drug doses.<sup>1</sup>



## SEIZURES

Seizures or fits can sometimes occur as a symptom of disease progression. The doctors and nurses will tell you if your child is at risk of having a seizure. There is an increased risk of seizures for children with pre-existing epilepsy, brain tumours, leukaemia in the spinal fluid and when there are changes in the blood chemistry. These children will often be prescribed medication that can be given by parents at home if a seizure happens.

Watching someone fit can be very distressing. However, knowing what to do if a seizure occurs can help reduce this distress.

- It is important to try and stay calm and to remove any objects that may cause injury
- Place your child on their side if possible
- Avoid putting fingers in a fitting child's mouth as biting may cause injury
- If you have been given medication to stop seizures, administer the medication
- This should stop the seizure promptly
- If you do not have medication or if the seizure continues phone the 1800 number for *RCH Paediatric Oncology Palliative Care Outreach Nursing Service* or your local health professional for advice
- Your child may need to be admitted to hospital for further monitoring and to commence medication to prevent further seizures occurring. The health professionals can arrange ambulance transport and hospital admission if needed

## EQUIPMENT FOR HOME CARE

Some children require very few aids to assist in caring for them at home. For older children and those with restricted mobility some aids will be useful for home. Wheelchairs or strollers may make it easier for children to participate in activities away from home. A soft mattress overlay or ripple mattress can help to prevent pressure areas when a lot of time is spent in bed. Using a hospital bed may make it easier to care for older children, as the bed heights and backrests can be adjusted making

positioning and access to bed easier. The use of shower and over toilet chairs, bath seats, and bedpans or urinals, can make bathing and toileting easier.

The staff caring for your child will coordinate the hire of any equipment needed for home care. A home visit by nurses or an occupational therapist to discuss what aids may help at home is often beneficial.



**PREPARING FOR YOUR  
CHILD'S DEATH**

## WHAT CAN WE EXPECT IN THE FINAL DAYS?

For the majority of parents, caring for their dying child will be their first close involvement with death. Parents are likely to have little knowledge of how their child may die and how they can best manage this difficult and stressful time.

It is our experience that parents usually wish to be prepared and want to know what to expect, but at the same time, in some ways they do not want to know, or may be too frightened to ask. Talking or reading about how your child may die and what to do at the time will be terribly sad and painful. It is hoped, however, that by providing parents with accurate information on what to expect that some of the fears often associated with a child's death can be alleviated.

As your child's cancer progresses, it usually becomes clear when death is approaching. The specific sites of cancer spread will determine the symptoms that are experienced. The following information is provided to assist in understanding the changes that may occur as the last days and hours approach. As every situation is different, these are only guidelines. Your child may experience only one or two of these changes. The doctors and nurses caring for your child will be able to give you specific details on the changes that may occur.

If you are caring for your child at home, you will have access to 24 - hour phone support from the *RCH Paediatric Oncology Palliative Care Outreach Nursing Service*. Some community nursing services also provide 24 hour on call for patients receiving palliative care at home.

### Increased sleeping

As the disease progresses many children spend more time asleep than awake. This increased sleeping is caused by a combination of factors. For example, the progression of the cancer can affect vital organs and will cause increased drowsiness; medications to control pain will also contribute to increased sleeping. If your child has cancer cells in the bone marrow this may cause anaemia leading to increased tiredness. Some children, however, will remain alert and responsive until they die.

### Restlessness and agitation

Some children become confused and agitated in the last few days of life, causing them to wake from sleep and become unsettled. This is not uncommon and can be caused by anxiety and fear, increased pain, nausea, decreased levels of oxygen or changes in the blood chemistry.

For children who are unable to speak at this time, displaying unsettled behaviour may be their only way of communicating that they are uncomfortable. It is important to check that there is no obvious reason for their distress, including a wet bed, do they feel cold or hot? or does their position need to be changed? Gently talking to your child and reassuring them that you are there will help in reducing anxiety. Simple measures like holding the hand and stroking the face can help to make them feel safe and secure. Playing music or videos, or sharing stories or prayers may also be comforting.

## WHAT CAN WE EXPECT IN THE FINAL DAYS?

If your child continues to be unsettled and distressed, it is important that you phone for advice, even if it is in the middle of the night. The distress may be from increased pain and the pain medication may need to be adjusted. This could be all that is needed. If the restlessness is from other causes then these may not be correctable and the focus needs to be directed at ensuring the child is comfortable. This can be achieved by giving other medications. If it is not possible to give oral medications, then the medication can be given rectally or subcutaneously through a syringe driver. These medications will decrease agitation but may also have a sedative effect, making it difficult for your child to speak to you. It is likely that they will still be able to hear you and will be greatly comforted and reassured by hearing familiar voices and knowing that the family is there.<sup>1</sup>

### **Loss of bladder and bowel control**

On occasion, as a result of weakness or relaxation of the muscles to the bladder or bowel, children may lose the awareness of the need to go to the toilet. If this happens, there are options available to ensure that the child's dignity is maintained and that they are kept dry and comfortable. Parents may choose to use nappies, disposable incontinence pads or disposable draw sheets. In some situations a catheter to drain urine may be considered.

### **Noisy/rattly breathing**

As a child becomes more drowsy the level of consciousness or awareness decreases. As a result it may be more difficult to clear secretions from the mouth. This may make breathing sound noisy or 'rattly'. This noisy breathing will cause no pain to the child, however family may find it very upsetting. Sometimes lying the child on their side will reduce this sound and having music on in the background can also reduce the awareness of this. Medications can also be given through a syringe driver to help reduce the secretions. If these methods are not helpful, a portable suction machine may be beneficial in gently removing excessive secretions from the child's mouth.

## WHAT CAN WE EXPECT IN THE FINAL DAYS?

### Circulation and breathing changes

With further progression of the child's condition circulation to the hands and feet is often reduced, making them feel cool to touch and pale, bluish, or mottled in colour. Putting on favourite socks and using a doona or blanket over the arms and legs can help. You may also wish to stroke your child's face, as sensation to the hands is reduced with impaired circulation.

Another change that is noticeable, is a change in the rate or depth of breathing. At times your child may even seem to stop breathing and then start breathing again. This is called "Cheyne-Stokes

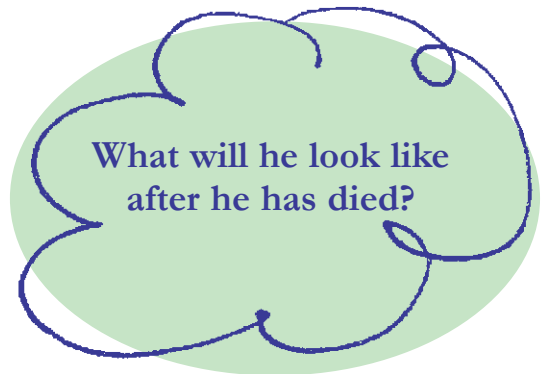
breathing" and may continue for a few hours or even longer until death occurs. This type of breathing causes no distress to your child, however, it can be very distressing for you and your family to watch.

If your child has been experiencing irregular breathing it is often hard to know when breathing has finally stopped. Parents often have an awareness of when their child has died. The most important role for parents at this time is to just be with their child for as long as they wish.

## DO PEOPLE LOOK DIFFERENT AFTER THEY DIE?

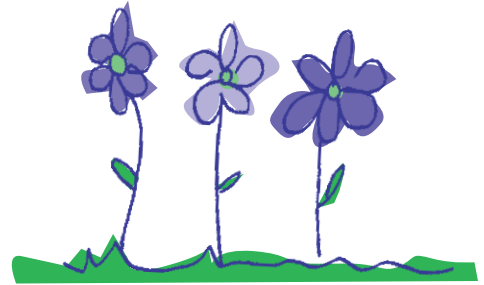
When a person dies the body changes occur over a period of hours. Your child will gradually feel cool to touch. The skin colour also changes as blood pools in different areas under the skin and can look like bruises. Due to the pooling of blood, the body will also become rigid. These changes will become more obvious with time and will be noticeable if you visit your child at the funeral home.

At the time of death some muscles in the body also relax and there may be loss from the bladder or bowel. There may also be some ooze from the mouth and nose. This can occur when you move your child for washing or undressing. Being aware of this helps you to be prepared when dressing your child in special clothes.



## CAN WE DONATE OUR CHILD'S ORGANS?

It is not uncommon for parents and teenagers to ask about the possibility of organ donation. Children dying from cancer are generally not able to donate organs or tissues because of the disease and prior chemotherapy. The one exception to this may be the donation of eye tissue for corneal transplants. Your child's oncologist and oncology CNC can provide you with more information on tissue donation if this is something you wish to explore.



## WHAT DO WE DO WHEN OUR CHILD DIES?

No amount of information or preparation ever completely prepares a parent for the death of a child. This will be a time of intense emotion and sadness for families. It is important for parents to know that when their child dies, nothing needs to be done in a hurry. Whether your child dies in hospital or at home, this is your personal time to be with your child and to say goodbyes. It is important that you take as long as you wish to be with your child. How long you spend with your child is an individual decision, often influenced by religious or spiritual beliefs.

It is a time for you, your other children, grandparents, close family and other people you want with you, to express love, sorrow, relief and regrets. You may choose to do this in many different ways and the following are examples of how families have chosen to spend this time.

- Listening to the child's favourite music while cuddling or talking to them
- Sleeping with their child for one last time
- Washing their child and dressing them in special clothes
- Taking family photos
- Taking prints of the child's feet or hands. This can also be done as a family collage to include parents and siblings handprints or footprints
- Cutting a lock of hair to keep



# WHAT DO WE DO WHEN OUR CHILD DIES?

## Dying at home

After your child has died, when you and your family are ready, you will need to phone your local doctor (GP) to let them know that your child has died.

Your local doctor will come to your house and certify in writing that your child has died. This letter is then given to the funeral director. The funeral director will obtain the formal medical certificate at a later time from your GP, paediatrician or oncologist. Parents often ask if they need to notify the police when their child dies. This is not required because the child's death was expected and the result of a progressive illness.

Many parents choose and visit the funeral director before their child dies to discuss how they want events to occur after their child dies and to talk about the funeral. This is then one less decision that needs to be made at the time. When you are ready, you can choose to drive your child to the funeral home or have the funeral director come to your home. Funeral directors are usually very flexible and will come to the house at whatever time suits you. They are also on call twenty-four hours a day but there may be an additional cost for work outside normal hours.

It is important for families to be prepared for what needs to occur if the funeral director comes to your home. For example, it is the policy of some funeral companies, to place people who have died into a body bag, to comply with Workplace Health and Safety Regulations, before placing them on a stretcher and taking them to the vehicle. If this is the case, you can ask that the bag be left open while your child leaves your home. You may wish for your child's doona to be placed over them or you may want your child to leave with a favourite toy. These special items can be kept for you by the funeral

director. When the time comes for you to give your child to the funeral director you may be overwhelmed with emotions. It is important to have the support of loved ones at this time.

## Dying in hospital

Much of the information outlined above also applies when children die in hospital. You will be encouraged to spend as much time as you need to with your child. You can also have other family members and friends at the hospital to see your child and say their goodbyes. The hospital staff are there to support you but they will also be trying to respect your need for privacy. This can sometimes be a difficult balance. you need more or less help from staff, do not hesitate to ask.

When a child dies in hospital, parents have the option of taking their child home for one last time, if they wish to. This can be arranged by talking to the nursing staff at the time. Others may prefer for the funeral director to come to the hospital when they are ready to leave, enabling them to leave the hospital at the same time as their child. If you have not chosen a funeral director and you want time to make this decision, then your child can remain in the care of the hospital until a funeral director has been arranged.

Leaving the hospital without your child will be a very emotional time for you, your other children and any others who are present. Hospital staff will be there to support you during this time.

# PLANNING FOR YOUR CHILD'S FUNERAL

Some families find it helpful to have time to think through the decisions about the funeral before their child dies. While this will be very sad to do, it may be easier than in the heightened distress of the hours and days immediately after your child has died. Decisions that will need to be made include; the type of service, whether you chose burial or cremation and where and when you want the funeral to take place.

Often older children and teenagers will have contributed to planning their own funeral and may have very definite ideas about how they wish the funeral to be conducted. The funeral director will also be able to offer suggestions and support as you plan the funeral. They will also assist you in the coordination of the practical aspects of the funeral.

Funerals are inevitably sad events, however, they can also be creative, positive and beautiful, when families are given the opportunity to make them so. It is important to realise that you and your family are able to make your own choices about the type of funeral you wish to have. This will ensure that the funeral will be personal and will reflect your child's life.<sup>1</sup>

The timing of the funeral is up to you and your family, and will depend upon your cultural and spiritual beliefs and wishes. You may want to discuss your ideas with the rest of the family, close friends, your child's school or a minister of religion. There is no requirement for a religious service, so you can plan and shape the funeral as you want.

There are many ways to capture your child's personality and to express your thoughts and feelings. An example of these ideas include:

- Painting or decorating the coffin
- Inviting people who have been important in your child's life to take part in the funeral.
- Choosing particular music, readings, poems, or mementos that have a special significance to your child.
- Some parents like to include a photo of their child in the order of service or display photos of their child at different stages of their life.
- Releasing helium balloons

After the funeral, it is not uncommon for parents to have little recollection of the service or who was there. You may wish to have people who attend sign a remembrance book and the funeral director can arrange this for you. You may also want to have the funeral videotaped, or ask those who spoke to give you a written copy of what they said. This can also be very helpful for young siblings who may have trouble remembering the day in years to come.

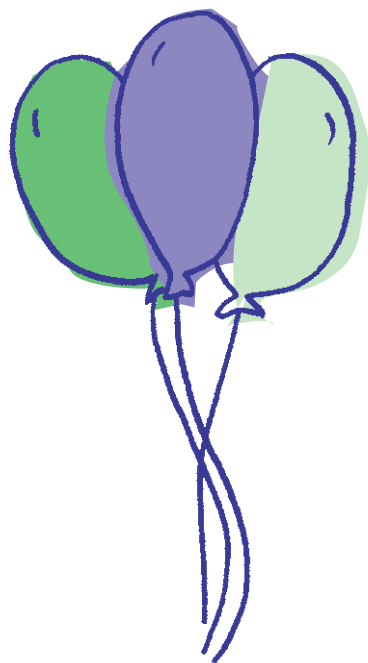
### Should children attend the funeral?

An issue that is often raised is whether children should attend funerals. The answer must be individualised but the general advice is that attending the funeral is helpful for a child if they are given appropriate preparation and support.

Attending the funeral allows children to feel included and helps prevent misunderstandings about what has happened to their sibling or friend's body. Preparation that is helpful includes: allowing children to be involved in planning the funeral if appropriate, encouraging them to ask questions about what will happen and giving them accurate information about what to expect. It is especially important to prepare children for the likelihood that many people, including their parents will be very sad and might cry and that it is all right for people to cry.<sup>1</sup>

Children are also likely to have some very direct questions about what will happen during the burial or cremation process. These questions can be very upsetting for parents to answer and you may want help from a religious minister, or the funeral director to help answer these questions for your child. The types of questions that children may have include "What will happen to the body?" "Why is he put into the ground?" "Can she feel anything?" "What if he's not dead?" and "What will her ashes look like?" These questions need honest, simple, accurate and sometimes repeated answers given in a caring and nurturing atmosphere.

This process is essential for grieving children, however, it can be distressing for families especially if they are not prepared.



**BEREAVEMENT AND  
THE FUTURE**

## HOW DO WE COPE NOW OUR CHILD HAS DIED?

The time immediately following your child's death may be a very busy time. This busyness often carries families through this emotional period. In the weeks following the funeral, however, life for everyone else seems to return to "normal." Family who have been visiting return home, friends go back to work and children return to school. This is often when grieving intensifies for many parents.<sup>2</sup>

There is now more time to stop and think, time to reflect on your child's life and realise that they are not coming back. Caring for your sick child has been a full-time, all consuming commitment and the sudden withdrawal from this after what has often been a very long period of illness can be very difficult. Parents are often left feeling very empty and alone. You may also be overwhelmed by the intensity of your emotions. It is important to know that these emotions are normal and are an important part of grieving.

There is no right or wrong way to feel at this time. You may feel many emotions. You may cry a lot, feel very sad, angry, empty and numb. Some parents feel a sense of relief after their child dies and feel confused and guilty for this. Being relieved that the situation you have struggled with is over is not the same as being glad that someone has died. Other children in the family may secretly be relieved that it is all over and that the family is no longer focused on caring for the ill child. They too may feel guilty for having these feelings.

For some families there may be feelings of regret. Looking back over their child's palliative care they may wish that certain events had happened

differently. It is important to realise that decisions made in palliative care occur during very emotional and stressful times. Families make decisions or choices that they feel at the time are in their child's best interest. It is easy with the wisdom of hindsight and retrospect to judge one's actions and to feel that different decisions could have been made. At the time however you do not have this luxury and it is important to not be too critical of choices that were made.

Parents often describe feeling as though they are not coping in the weeks following their child's death. Tasks that they could do easily now seem more difficult. Being unable to think clearly, lack of concentration and poor memory are common concerns. Parents often report such things as not being able to find their car in a car park, losing their sense of direction and forgetting people's names. These problems are often worsened by poor sleep and a lack of appetite, which can contribute to physical and emotional exhaustion. It is important to be gentle with yourself and take the time you need to care for yourself. Try to eat a balanced diet and have time for rest and some regular exercise. This may help you have the energy to get through each day.<sup>3</sup>

## DO MEN AND WOMEN GRIEVE DIFFERENTLY?

Just as no two people grieve the same, men and women often grieve differently. It seems more socially acceptable for women to cry and talk about their feelings. Society often expects men to be strong, to not cry and to take care of the women and children. People may become uncomfortable when men express their grief. Fathers may be continually asked how the child's mother is coping but not themselves. A father may feel that no one acknowledges that the child was his too, and that he is expected to make all the arrangements and support everyone else. Men may be "neglected" grievers.<sup>3</sup>

For these and many reasons, men's grief may appear in the form of physical symptoms, such as work stress, rather than what it really is. Men may show their anger and irritability more readily than other emotions related to grief. They may grieve very privately and cover up feelings in other ways, such as working long hours, or drinking excessive amounts of alcohol, hoping that this will distract them, help them sleep or relieve painful feelings.

Many people believe that the child's death may make the parent's relationship closer. At times, however, parents may not feel close to each other in their grief and may find it difficult to comfort each other and cope with their own emotions. The following suggestions may be helpful.<sup>3</sup>

- Make the time to be alone together, talk about your child and share your grief
- Try not to expect too much too soon from each other
- Listen carefully to your partner and gently watch out for them
- Keep an open mind and learn more about each other
- Think about what you say before you say it
- Seek professional help if necessary

Although men and women may express their emotions differently, if you are able to share your grief and talk about your child then you may not feel as isolated in your grief. It is important to keep in mind that even the strongest of relationships can be challenged by the death of a child. It is often by leaning on each other at vulnerable times that you find strength and comfort in your relationships.

## CARING FOR OTHER CHILDREN IN THE FAMILY

Children of all ages experience grief. Children may differ widely in their reactions to their sibling's death, depending upon their age, relationship with their sibling and their own personality. Children are likely to need continuing information and reassurance about their sibling's death at different stages of growing up. At successive stages of their development they may ask for more details about their brother or sister's illness.

Children are often concerned that they may not remember their sibling as they grow older or that their memories will not be as strong. Helping your child/children to create a memory book about special things they remember about their sibling can help to reduce this fear. It can be a special memento to keep and look back on in years to come. It also provides an opportunity to say goodbye creatively and to explore feelings through the use of drawings, photos and writings.

It is not uncommon for young children to regress in their development as a response to the loss of their sibling. Their distress and sadness may be manifested through sleep disturbances, temper tantrums, clinginess, poor attention and moodiness. Children may revert to behaviours that they had previously outgrown, such as thumb sucking and bed-wetting. They need plenty of reassurance that they will continue be cared for and are very much loved by the family.

Children need to be encouraged to express how they feel and to talk about their sibling. Older children may find diary writing, poetry, sports, music and art can be great outlets for their feelings. If your child's reactions seem extreme or prolonged it is important to seek professional advice. This can be accessed by contacting the hospital social workers or through counsellors at your child's school.



## WHERE TO GO TO FOR HELP

It can be hard to know where to seek help after the death of your child. Grief can be a lonely, unique and often very private journey. It may be difficult to share your grief with another person however close that person is. Even with the best intentions people may not know how to offer comfort. Sometimes wrong things are said or well meant words can sound unkind. Statements such as “at least she is no longer suffering”, “he’s at peace now”, “we know how you feel” or “it was for the best” are intended to provide comfort but instead can make you feel angry and upset.

People often wrongly believe that it is good for parents to be distracted from their grief and may try to keep you busy or encourage you to rush back to work. Try to find friends or family who do not expect you to put on a happy face and are comfortable with you expressing your feelings. Telling your story and talking about your child helps in healing. If friends or family sense that you are able to talk about your loss it may help them to recognise your desire to also reflect on the joy of loving your child and to share your memories.<sup>3</sup>

**Bereavement or grief counsellors** can provide a safe environment to express your grief. Finding the opportunity to talk with someone outside the normal circle of friends can be of great help. Bereavement counselling aims to provide support which may assist you to understand your feelings and responses; understand and cope with the reactions of others; readjust and focus your life, and identify additional support within the community. If you wish to explore this option, your social worker can give you details of counsellors or grief support groups in your local area.

The loss of a child is not something people “get over” like recovery from the flu. Instead the loss becomes a part of you and the full sense of the loss does not occur all at once. You will grow older with your memories of your child who has died. Special events such as birthdays, family gatherings and anniversaries will always be reflective times and will reinforce how much your child has influenced yours and your family’s lives.







# **FURTHER INFORMATION**

## BOOKS FOR FURTHER READING

Listed on the following pages are books that may assist parents and children to deal with feelings associated with dying, death and bereavement. These books are only a small sample of the books available. When selecting books to read with children it is important to review the book yourself before reading it with a child to ensure you are comfortable with the content material. Bookshops and libraries have increasing numbers of books about grief. It is wise to shop around for ones that are meaningful to you. Many of the books listed below are available for short-term loan from the Oncology Unit, RCH.

### BOOKS FOR YOUNG CHILDREN

#### ***Gentle Willow A Story for Children about Dying***

*Joyce Mills and Michael Chesworth. Magination Press: New York, 1994.*

A story written for children with a life threatening progressive illness. This comforting story will also help children dealing with the death of a sibling or friend. It provides children and those who read the story with them a transformational way of viewing death and dying. (5 to 8 years)

#### ***I Had a Friend Named Peter – Talking to children about the death of a friend***

*Janice Cohn and Gail Owens. Morrow Junior Books: New York, 1987.*

An introduction by the author discusses questions parents and teachers may have about talking to children about death. The story is about Betsy, who learns of the sudden death of her friend Peter. Her parents answer her questions simply and honestly.

“Will I die too?” Will Peter be cold and lonely when he’s buried?” “Will the funeral be scary?” “Did I somehow cause the death?”

#### ***Lifetimes: A Beautiful Way to Explain Life and Death to Children***

*Bryan Mellonie & Robert Ingpen. Hill of Content: Melbourne, 1983*

With large illustrations the book tells about beginnings, endings and living in between for plants, animals, and people. Dying is as much a part of living as being born. (3 to 6 years)

#### ***The Dead Bird***

*Margaret Wise Brown. Addison-Wesley: Reading, Massachusetts, 1958.*

A group of children find a dead bird, examine it carefully, hold a burial service and decorate the gravesite every day until they forget. (3 to 5 years)

#### ***The Tenth Good Thing about Barney***

*Judith Viorst. Aladdin New York: Paperbacks, 1971.*

Barney the boy’s cat dies. How to write a eulogy? Barney was, brave and smart and funny and clean and cuddly and handsome and he only once ate a bird, it was sweet to hear him purr in my ear and sometimes he slept on my belly. The 10th good thing about Barney is he is in the ground he’s helping the flowers to grow. (5 to 8 years)

### BOOKS FOR OLDER CHILDREN AND TEENAGERS

#### ***How Teenagers Cope with Grief – Something I've never felt before***

*Doris Zagdanski, Melbourne: Hill of Content, 1990.*

Teenagers share their experiences relating to the death of a parent, grandparent, sibling and friend.

#### ***Memory Book for Bereaved Children***

*Kathleen Braza & Bonnie Bright.*

*The Holy Cross Hospital Grief Centre:  
Salt Lake City USA, 1989.*

A booklet for children and teenagers to complete and keep. Children may fear that they will forget the person who has died as they grow older. A memory book gives them the opportunity to say goodbye, write down their memories and express their grief.



#### ***Straight Talk about Death for Teenagers***

*Earl Grollman. Beacon Press: Boston, 1993.*

“How come when someone dies people forget about us? Everyone is trying to help the little kids or parents but what about us? Don't we count?”

#### ***Thoughts – A teenagers response to a crisis***

*Darren Crewe. Ronald McDonald House, Parkville Inc. Victoria. 1997*

The thoughts and feelings of Darren a 14 year old with relapsed Leukaemia are written and illustrated in his own personal journal. His thoughts have been published to provide comfort and knowledge to others who have to face death.

#### ***Two weeks with the Queen***

*Morris Gleitzman. Sydney: Pan MacMillan, 1989.*

A humorous novel about a boy's effort to help his younger brother who has incurable cancer. Colin attempts to by pass Buckingham Palace and visit the Queen. The novel successfully highlights the needs and concerns of siblings.

### BOOKS FOR PARENTS

#### ***A Child Dies: A Portrait of Family Grief***

Joan Hagan Arnold & Penelope Buschman. Philadelphia: The Charles Press Publishers 1994.

The authors offer practical advice and compassionate understanding of the suffering, loneliness and despair of the death of a child.

#### ***Are You Sad Too? Helping Children Deal with Loss and Death***

Dinah Seibert, Judy Drolet and Joyce Fetro. California: ETR Associates, 1993.

Suggestions for parents, teachers and other care providers for children up to the age of 10 years.

#### ***Healing a Father's Grief***

William Schatz, USA, 1994.

Written by a father whose son died following a six-year illness with Leukaemia. After four years of working through his own grief, with other grieving fathers in The Compassionate Friends, the author shares what he has learnt

#### ***Helping Children Cope with the Loss of a Loved One – A Guide for Grown ups***

William C. Kroen. Free Spirit Publishing Inc. Minneapolis, MN. 1996.

“To be able to grieve appropriately and cope with loss before, during and after a death enables a child to grow up free of guilt, depression, anger and fear. When we help children heal the pain of the death of a loved one, we are giving them important skills and understandings that will serve them the rest of their lives” - Dr William Kroen

#### ***Help Me Say Goodbye – Activities for helping Kids Cope When a Special person Dies***

Janis Silverman. Minneapolis: Fairview Press, 1999.

An activity book for families with young children to help prepare the children for the death of a loved one.

#### ***Single Parent Grief***

Sherokee Ilse. USA, 1994.

For men and women who are single and dealing with the death of a child. Answers the question “Is death different for a single parent?”

### ***Talking About Death – A Dialogue between Parent and Child***

*Earl Grollman. Boston: Beacon Press, 1990.*

A guide for adults and children to read together, featuring a read-along story and answers to questions children ask about death.

### ***The Bereaved Parent***

*Harriet Sarnoff Schiff. New York: Crown Publishers Inc., 1977.*

The author discusses the day-to-day decisions faced by bereaved parents. Including – facing the funeral, considering a memorial, accepting the change in family life, protecting surviving children, rebuilding relationships and coping with delayed reactions. Practical suggestions are given for addressing these issues.

### ***The Grieving Child – A Parent's Guide***

*Helen Fitzgerald. New York: Fireside Publishing Co, 1992.*

The Grieving Child offers practical advice for helping a child cope with the death of a loved one. Parents will find useful suggestions for dealing with a child's emotional responses and advice to help the child adjust to life without their sibling.

### ***The Death of a Child – A Book for families***

*Tessa Wilkinson. London:*

*Julia MacRae Books, 1993.*

During her work as bereavement counsellor for the Helen House Children's Hospice, the author realised the need for a book about death that spoke to both children and parents. The book includes a section for parents, a story to read with children and a selection of readings, poems and prayers.

### ***“What's Dead Mean?” How to help children cope with death. A book for talking, drawing, pasting, sharing . . .***

*Doris Zagdanski, Hill of Content: Melbourne, 2001.*

This activity book is designed for children 3 – 7 years and adults of all ages. It is designed to encourage communication between adults and children about the subject of death. It especially helps adults explain the words that children hear when someone they know has died.

# LISTS OF COMMUNITY ORGANISATIONS

Listed below are some examples of local and national organisations that may be useful to families. Access to other agencies can be arranged by contacting your social worker.

## ORGANISATIONS

### Camp Quality

P.O. Box 190  
Bulimba QLD 4171  
Phone: 07 3899 9011  
Email: [cqsthqld@powerup.com.au](mailto:cqsthqld@powerup.com.au)  
Website: <http://www.campquality.org.au>

### Canteen – The Australian Organisation for Young people Living with Cancer

11 Tuffton Street  
Bowen Hills QLD 4006  
Phone: 07 32525188  
E-mail: [admin@canteen.org.au](mailto:admin@canteen.org.au)  
Website: <http://www.canteen.org.au>

### Compassionate Friends

(support for bereaved parents)  
P.O. BOX 218  
Springwood QLD 4127  
Drop in centre – Mon, Tues & Fri 9am-3pm  
505 Bowen Terrace  
New Farm  
Phone & Fax: 07 32542657  
Email: [tcfqlld@powerup.com.au](mailto:tcfqlld@powerup.com.au)  
Website: <http://www.uq.net.au/tcfbrisbane>

### Children’s Leukaemia and Cancer Society

PO BOX 295  
Red Hill QLD 4059  
Phone: 07 3252 4719  
Email: [elizabeth@clcs.org.au](mailto:elizabeth@clcs.org.au)  
Website: <http://www.clcs.org.au>

### Karuna Hospice Service

“Rosemount”  
Cartwright Street  
Windsor QLD 4030  
Phone: 07 3857 8555  
Email: [Karuna@karuna.org.au](mailto:Karuna@karuna.org.au)  
Website: <http://www.karuna.org.au>

### Kids with Cancer

Community organisation providing financial assistance for funerals. A social worker referral is required to access this service.

### Leukaemia Foundation of Queensland

PO Box 222  
FortitudeValley QLD 4006  
Phone: 07 3250 0500  
Email: [info@leukaemia.com](mailto:info@leukaemia.com)  
Website: <http://www.leukaemia.com>

### Redkite

Community organisation providing emotional support services, financial assistance, educational services, music therapy, family support and activity days and bereavement support. Your social worker can help you access this service.  
Website: <http://www.redkite.com.au>

# LISTS OF COMMUNITY ORGANISATIONS

## Make A Wish Foundation

90 Auburn rd  
Hawthorne Rd  
Hawthorne VIC 3122  
Toll free Phone: 1800 032 260  
Website: <http://www.makeawish.org.au>

## Queensland Health

Palliative Care Information Services  
Mon – Friday 9.00 – 5.00pm  
Phone: **1800772273**

## Queensland Health

Centre for Palliative Care Research  
and Education (CPCRE)  
Block 4F  
Royal Brisbane Hospital  
Herston QLD 4029  
Phone: 07 3636 1449  
Email: [cpcrc@health.qld.gov.au](mailto:cpcrc@health.qld.gov.au)  
Website: <http://www.cpcrc.com>

## Cancer Council Queensland

PO Box 201  
Spring Hill QLD 4004  
QLD Cancer Fund Cancer Helpline: 131120  
Email: [helpline@qldcancer.com.au](mailto:helpline@qldcancer.com.au)  
Website: <http://www.qldcancer.com.au>

## Starlight Children's Foundation

GPO Box 1565  
Brisbane QLD 4001  
Phone: 07 32239400  
Email: [qld@starlight.org.au](mailto:qld@starlight.org.au)  
Website: <http://www.starlight.org.au>

## The Palliative Care Association of Queensland

Unit 3/21 Enoggera Terrace  
Red Hill  
Q 4059  
Phone: 07 33683704  
Email: [info@pallcareqld.com](mailto:info@pallcareqld.com)  
Website: <http://www.pallcareqld.com>

## Xavier Children's Support Network

– provides assistance to families with children  
who have high support needs.

284 Pine mountain Road  
Mount Gravatt East QLD 4122  
Phone: 32168811  
Website: <http://www.xcsn.org>



## REFERENCES

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3. Royal Children's Hospital Brisbane, Social Work Department, **Parent Bereavement Booklet**. 2001
4. World Health organisation. **Cancer Pain relief**. Geneva: World Health Organisation.1986
5. Noyes M, Irving H. The use of transdermal fentanyl in paediatric oncology palliative care. **American Journal Of Hospice and Palliative Care** 2001; 18(6) 333 - 341

# HEALTH PROFESSIONAL CONTACT DETAILS

This page is for parents to record contact details of health professionals who may be involved in their child's care.

Oncologist \_\_\_\_\_

Oncology CNC / Nurse specialist \_\_\_\_\_

Oncology Ward \_\_\_\_\_

Oncology Day Unit \_\_\_\_\_

Oncology Social Worker \_\_\_\_\_

Oncology Occupational Therapist \_\_\_\_\_

Oncology Physiotherapist \_\_\_\_\_

Paediatric Oncology Palliative Care Outreach Nursing Service \_\_\_\_\_

Local Paediatrician \_\_\_\_\_

Local Hospital (Paediatric Ward) \_\_\_\_\_

General Practitioner \_\_\_\_\_

Community Nursing Service \_\_\_\_\_

Local Pharmacy Name \_\_\_\_\_

Ph \_\_\_\_\_

Local Counsellor Name \_\_\_\_\_

Ph \_\_\_\_\_

Other Contacts Name \_\_\_\_\_

Ph \_\_\_\_\_

Name \_\_\_\_\_

Ph \_\_\_\_\_

Name \_\_\_\_\_

Ph \_\_\_\_\_







Children's Health Queensland Hospital and Health Service  
Queensland  
[PPCS@health.qld.gov.au](mailto:PPCS@health.qld.gov.au)