

Pediatric Palliative Care Family Education

Making Hard Decisions

- ◆ Introduction
- ◆ Choices about the approach to care: from active treatment to palliative care
- ◆ Choices about quality of life
- ◆ Choices of the place for care: supports in your community and at home
- ◆ Critical choices about antibiotics
- ◆ Critical choices about blood products
- ◆ Critical choices about tube feedings and fluids
- ◆ Critical choices about DNR (do not resuscitate)
- ◆ Preparing to take your child home: discharge care plan and palliative care checklist

Symptom Management

- ◆ Pain
- ◆ Breathing difficulties
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- ◆ Fatigue / energy
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- ◆ Confusion / dementia

Other Resources Available Through C&W and Canuck Plan Children's Hospice

- ◆ Making a decision about autopsy (BCCCH Booklet)
- ◆ After the death (BCCCH pamphlet about funerals and services)
- ◆ Griefworks Guide
- ◆ Finding Your Way - Grieving the Death of Your Child (CPCH)
- ◆ Other grief support information:
 - www.canuckplace.org
 - www.griefworksbc.com

Parenting a Dying Child

- ◆ Precious Time: suggestions for making the most of the time you have
- ◆ Emotional Distress: tips for parents, how to help your child
- ◆ Personal Care: mouth care, skin care, hygiene, bathing
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Talking About Dying

- ◆ Talking to a dying child
- ◆ Talking to siblings
- ◆ Talking to family and friends
- ◆ Talking to classmates

Honour the Spirit and Caring for Your Child After Death

- ◆ In the Days After Death: planning a funeral, creating a eulogy, in the weeks and months after the death

Parenting a dying child

Precious Time

You will not regret the time you have spent focussing on your child rather than the disease or the “battle.” This is true whether your child survives or dies. Regrets often focus on time lost to the “battle.”

Parent voice:

Weeks after Sal died I was still stuck with ‘what ifs’. What if I had insisted on another transfusion? Maybe if we had tried pushing the diet and vitamin supplements Jan told us about we would have had another year? When I would go on and on about this, my good friend used to remind me about how carefully I made each decision for my child, how hard I worked at thinking through what was best for Sal. She always helped me to focus again on why I made the decisions I did.

Parenting a child through life is the most important and the hardest work most of us will do. Many manuals have been written offering advice and still we struggle. Parenting a child through dying is overwhelming. It is hard to find helpful guidance.

Many people talk about “finding meaning” or making the experience “meaningful.” It is challenging to know what this means, let alone how to do it. How can the loss of a child ever make sense? So what are these people trying to tell you? They are not trying to get you to make sense of your child’s condition or to find comfort in some philosophy. They are encouraging you to make the time special, to be mindful of how you are connecting to your child. It means thinking about what your child gives you and what you give your child.

In our experience so many parents miss the very best chances for joy and closeness. This is because they remain focussed on a “fight for the cure” no matter how improbable, during those months when the child still has the energy to invest in life. They may choose to push nourishment rather than the pleasure of food when the child still has an appetite. They may forgo a birthday party for a blood transfusion. Consider what is being lost with an ongoing battle for the cure. Try not to leave it too long to start focussing on quality above cure. Perhaps today is the day to start.

A parent framed his regret about how he had used his time this way: *“I have journals filled with every lab test result, with blood counts, pain measurements, calories eaten. Why did I keep all these records and no record of the cute things he said?”*

The guiding principle must surely be to use every chance you can to create pleasure and joy. And when this is no longer possible, to move toward an inner peace for you and your child.

Love lives in the space between people who are reaching out to one another.

Precious time can be lost as easily as gained

We can lose precious time when we don't recognize or seize the moments. The moments may be a good day, a good morning, a good 10 minutes. A moment may be a child's question or comment which serves as an opening for an intimate talk. A moment may be a storybook or a song that opens the door to a memory. A moment may be a good laugh. A moment may be a chance to express love, quiet fear, or make a new discovery.

Consider how you can add precious time to your child's life – and yours.

- * **Use the opportunity that comes with a good day, a good morning, a good 10 minutes. Forget chores in favour of fun at these times.**

Ideas:

- ♦ Make an "I wish I could ...list." Pick something from the list to do when your child has energy to do it.
- ♦ Take a trip to the mall/town and invite your child to buy a gift for anyone he chooses. (Set a dollar limit!) Suggest he write or dictate a card to go with it. This is not just a fun activity. It gives a chance for your child to express love.
- ♦ Invite your child's best friend for a visit. Take a photo of the two of them together.
- ♦ Sit under a tree in the garden with your child on your lap.

- * **Pick up on a child's question or comment**

Examples:

"I just love puppies". Maybe there is some special outing you can make around puppies - like a pet shop visit or borrowing a puppy to take for a walk. Find a breeder with a new litter. Chat about where each puppy might go when it leaves.

"How come I can't see the moon tonight?" This can be a rich moment. You can talk about how one can know that something is there even if you can't see it.

"I wonder what Jamie is doing now." If the time is right, this can lead to a meaningful talk: *"Isn't it strange how people come into our minds. We think about them even when they are not there in the room with us."*

Adding precious time to life may be adding an extra day. It can also be using a given day well.

* Use the power of stories and songs

Read stories together. If your child chooses the same book or story often, consider why this is special. Is there a message in it? You can make that book a precious thing. Perhaps write a special message in it for your child. Perhaps ask your child for a special message to write for the family. Write it into the book and have your child sign her name. Record a sibling reading a story to your non-verbal child. Try to comment, as she reads, on her sibling's smiles and responses. This can become a memory treasure.

Make your own storybook or scrapbook together. This can be a way to reflect on your child's life. It can include lists of best times, things I am good at, holidays, remember whens and so on. Type it up, leave space for photos and drawings. (Keep a tape recorder handy.) Older children may have a pop song they sing often. Ask your child to teach you that song. Record the two of you singing it together.

* Do some family art projects

- ♦ Many children (and adults) find it hard to express feelings or ideas with words. Crafts can be a different way. Ideas:
- ♦ Have a playtime when everyone makes a card for each other.
- ♦ Do family handprints.
- ♦ Cut up old family photos and magazines to make an album of funny people from them.
- ♦ Make pictures and reflect on them.

* Create a chance for a good laugh

- ♦ Nothing brings down the tension level like a laugh or silly time! It is a relief for everyone to laugh together. Watch for chances to be silly.
- ♦ Help your child play a joke on the doctor, dad, or visitor.
- ♦ Get a funny movie and laugh together.
- ♦ Remember funny family events. Replay funny videos of the family if you have them. If you don't, maybe make a few. You can include everyone if you use props rather than words to create the fun. For example, how about making a video of everyone modeling a hat or costume.
- ♦ Make up funny words to a tune you know well.

Parent voice:

Nicholas's brothers and sisters often started to do silly kidstuff with Nicholas - make rude noises, bounce on the bed and so on. It drove me crazy. I wish now I had encouraged it. Sibling time is very precious time. Grown ups can't be kids and kids don't really want to be grown up all the time.

* **Take every chance to express love or quiet fear.**

- ♦ Cuddle up together as often as possible.
- ♦ Allow your tears when they come. Use them as a precious moment in which you can say, “I’m crying because I love you so much.” “I’m crying because I wish this moment could last forever.”
- ♦ If your child is crying, see that as a chance to talk about feelings and what makes us cry. Cry with your child if it comes naturally.
- ♦ Not all feelings are as comfortable as tears. Outbursts of anger can also be turned into a healing moment. (See the next section on “Emotional distress.”)
- ♦ Put up a board with photos of everyone who loves your child. Take photos of them with your child when they visit. Add them to the board so it fills up with love.

* **Discover new things about each other**

- ♦ Tell your child about the sweet things he did as a baby that you remember now and always will. Make a list of the cute words he used.
- ♦ Tell your child stories about you as a child. What kinds of mischief did you get up to?
- ♦ Play a game where you tell each other “something you don’t know about me.”

End note:

Good times together are rich in themselves. If these times have drawn you close and created memories, they will be the precious times. These are the times of no regrets and “sadness that is sweet.”

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Parent voice:

We learned so much about each other in the last few weeks of Amir’s life. One of the best hours we had was when I described how it felt to have him in my belly. I told him about all the stories his father and I made up about what he was like. I told him about how we gave him many funny names. He loved it! Funny - I have never done that with my other children.

Parent voice:

We needed to be reminded to make emotional and physical space for our child. We were so intent on making every moment count. We wanted someone with him all the time. We had his room crowded with stuff – there was nowhere for friends to be when they came. We took things in hand. We moved Matt into the family room - it was a bigger room. We went through each item on the wall of the bedroom and asked if he wanted it up again or in a drawer. Then, we made sure there was time for him to be on his own each day. When he didn’t want alone time he let us know!

Parenting a Dying Child

Emotional distress

The health professionals will give you many handouts with advice on how to parent a child through the end stages of his life. Many of these will ask you to “stay calm” so that you are a support for your child and others in the family. Staying calm in the face of the stormy emotions swirling inside you, and the storms blowing up around you, is a challenge. The challenge is not one you may always be able to meet.

No one expects that you will be in control of yourself all the time. Nor can you be responsible for making all the fear, envy, anger and sadness go away for every member of your family. But these natural feelings cannot be ignored. This section is offered to you with humility. We hope you will find a few bits of wisdom that will help you respond to the emotions of distress that tear through all families facing grief of this kind.

Consider what you can draw on for your own emotional support

Parents are the centre of their child’s life. Your child will draw his strength and courage from you. How the parent responds and copes directly affects how well the child can respond and cope. From whom and from where will you draw your strength and courage?

What restores your soul?

- * Think about what has helped you through difficult times in the past – meditation, prayer, exercise, physical intimacy or group activities like singing in a choir? Give time to these things. You will pay it back to your sick child and family many times over.
- * Who are the people you can turn to for support and comfort?
There may be times when you must let go and fall apart. You may have tough feelings you need to talk through and understand. To whom can you turn? The obvious people may not always be the best. Your partner may be too tense to take on your emotions. Your mother may be more controlling than helpful when she is fearful herself. Think about who in your life, friends or advisors, you can trust to listen and not judge. Who gives you a lift? Who knows what to say and when not to speak? Ask these people for help. Reach out for them when you are in need. Hard as this may be for you, you will need them.
- * Find ways to kindly, but firmly, keep short your time with people who drain your emotional energy. You have none to spare now.
If you find that there is no-one who is able to offer enough support, or helpful support, ask a healthcare professional to suggest some counsellors who may be useful to you.

*One parent described it this way,
Sometimes I felt like I was trying to
hold back the sea tides of rage in the
morning and then make the sun
shine in the dark nights of despair! I
couldn't do it everyday...no one can.*

**Don't turn aside your feelings
and needs.**

**When you ask someone for help,
you do her great honour. She will
be thankful to have a way to be
helpful.**

Consider how you support your child through times of distress

Children who understand that they may not live to grow up can grieve this loss very deeply. Some may become depressed. These emotions are a reasonable response to the unfairness of their life now and in the future. Like adults, children experience and express their grief in different ways. Depression and grief have many masks. Watch for:

- ♦ **anger:** from irritation to rage;
- ♦ **fear:** from clinging and dependency to terror;
- ♦ **sadness:** from dullness to despair;
- ♦ **withdrawal:** from lack of interest to loss of concentration to shutting out the world;
- ♦ **helplessness (regression):** from confusion to loss of control. (This can show itself in the loss of skills, e.g., the child who has learned bladder control goes back to wetting, or the child who has learned to control his impulses - e.g., waiting his turn - now snatches and hits);
- ♦ **guilt:** from self-blame and shame to over concern for others, especially parents.

* Be accepting of your child's hard feelings

The most important thing you can do for your child is to have the courage to see, hear and respond to the hard emotions he may have – the fear, anger and depression.

Accepting these as part of your child's being at this time allows your child to share with you. Sharing is supporting. Sharing halves the burden of grief.

* Be sensitive to the many ways children show their feelings

Some children act out feelings (temper tantrums, tearfulness). Others turn inward (withdraw, sleep, lose interest, pretend or deny feelings). Pay attention to what your child is doing. It gives clues to what your child is feeling.

* Help your child name and allow his feelings

Even if your child speaks easily and has many words, he may not be able to connect with, or express, the feeling inside. Encourage your child to express concerns. Notice your child's behaviours and comment on them: *I notice you looked nervous when I talked about the home care nurse coming today. Can you tell me what you are worried about?*

Will my child lose hope? Will she have fears that I can't fix? How do I respond to his tears and worries?

Parent voice:

There were times when I responded to my child's outbursts with outbursts of my own. I acted out my pain when he said hateful things. I had terrible guilt afterwards. I forgave him easily enough, but I had to work on forgiving myself.

Reflect the feeling behind what your child says.

You told your brother he was not nice when he left to go to his soccer game. What were you feeling? Were you feeling sad that you could not go too?

It seems like you get mad when I ask you to take your medication. .. Is that right? I wonder if your medication reminds you that you are sick. (Allow time for the child to agree or disagree.)

* **If possible find a safe way to let go of the feeling**

Work with your child to find ways to get the feelings under control.

- ◆ Provide outlets that match the feelings.

Let's draw a picture of the medication and tear it up."

Let's give the medication a gross name! What shall we call it? Would you like to make a label with the new name and then we will stick it on the bottle?

It isn't OK to hit your sister or the table with the tennis racket. I won't let you do that but you can hit your mattress with that tennis racket if it helps get rid of the bad feeling.

I'm feeling sad too; let's give each other a long, long hug.

- ◆ Use distractions like fantasy and storytelling to take your child into "another world," a happier place. Lead your child into imagining things with you, Using a quiet, relaxed tone, lead your child like this:

Remember where we camped the first night surrounded by green trees—can you picture that?

I see the hummingbird that visited, do you....?

I hear the water against the rocks...

Let's plan some adventures for our imaginary camping trip.

That night we made pancakes, what shall we make tonight...?

* **Use medication if it will help**

In the past few years, we have learned that careful use of medication can be helpful at times of great anxiety or distress. Talk with a healthcare professional about it. Our goal is always to help the child cope in order to tap into her own inner strengths.

Building stories can be a creative activity to do together. You can also do some of these as a tape-recording for your child. She can then play them at any time. She might like to record a story for you.

A word about anxiety and fear

It is normal for a child who knows he is very sick to have times when he is afraid. The greatest fear for many parents is talking to their child about death. (Refer to the section on this topic). But don't assume all the child's fears are to do with the sickness or death. All children have fears because so much of the world is unknown. The fear may be of the shadow on the ceiling or the monster under the bed.

Learn how to use a calm voice and manner to be a calm presence:

- ◆ Speak in a slow, low voice.
- ◆ Relax your body, slow and deepen your breathing.
- ◆ Slow down your movements.
- ◆ Remind your child that you are there to keep him safe.

What may help:

- ◆ Sort out with your child what is a real threat and what is not.
- ◆ Tell your child often that you will be with her to keep her safe. Tell him that he can call for you when he is afraid.
- ◆ Talk about the fears you had when you were a child and what you did about them.
- ◆ Try to offer your child some real choices when possible.

Would you like your grandma to stay with you when I go out today or shall we ask Sarah to come and be with you?

When you wake in the night and you feel afraid, do you want to come into the cot in our room, or shall I come into your room?

A word about anger:

One of the most frightening aspects of grief or depression is its anger mask. This is especially hard when the anger is turned against the parent - the one trying hardest to "makes things better." The parent is IT because the child feels safest with you. No matter how "bad" the child acts, he knows that this person will always love and care.

What may help:

Anger is just another emotion and cannot be denied. However, you cannot allow the anger to hurt anyone. If your child has no control over the impulse to hit, bite, yell or insult, you will need to set and maintain the limits. Think about this as a return to baby behaviour - a loss of a self control skill. Respond as you would to a younger child behaving in this way.

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Many of the fears children have are about their lack of power and control. Your strength is their main comfort. This is why they fear less when you are calm beside them. If the parent reacts with fear, or is not present, the child feels less safe.

Choices give the child a sense of control.

Talk your child down. You might say, *I'm here for you. If it's hard for you to stop hitting and yelling, then I will help you. I will hold you gently until you feel quiet inside. I will speak softly in your ear to remind you to speak softly too. Nothing is going to get better until you are quiet inside and out.*

When you need more than parenting skills

Talk with a healthcare professional about what you are seeing. Some children will need more help getting on top of their emotional distress than good parenting. Distress storms may batter too hard at a family. These storms may leave emotional shambles. Call on the health care team for help if this is happening in your family.

End note:

So much of this is about just being with your child to hear and respond to each other as child and parent. It is not about fixing or making everything all better but being present.

As one parent said to his teenage son: I just want you to know this one thing and remember it always – I'm on your team. Win or lose, we're going to do it together.

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CANUCK PLACE
CHILDREN'S HOSPICE

Personal care and hygiene

Except for your loving presence, there is probably no better way to make your child feel cared for, than to keep her clean and fresh smelling. Being clean gives a sense of wellbeing. It also helps prevent infection and skin problems. You may find as time goes on that you need help with this care. It may be good to see if there is another family member whom you can involve sometimes. This means your child will be used to someone else being there and doing some of the care of the body.

Bathing

A bath will refresh your child. Give him a bath/shower or help him bathe everyday. Your health care professional can get you bath/shower chairs and lifting equipment if you need it.

If your child can't get into a tub/shower:

* Give a bath in bed:

- ◆ Bring warm water and soap to the bedside with a washcloth and several towels.
- ◆ Place a towel under the part of the body you are washing so the bedding stays dry.
- ◆ Wash one part at a time. Cover other parts of the body with a light blanket to prevent chilling.
- ◆ If your child is not up to a full bed bath try to wash his face, hands, underarms, and genitals.

* Wash hair in bed:

- ◆ Shift your child's head so that it hangs slightly over the edge of the bed. Put one side of an open plastic garbage bag under your child's head. Cut a hole at the other end of the bag. Place the end with the hole into a bucket on the floor.
- ◆ You might need someone to help, lots of towels, shampoo and pitchers of warm water close at hand.
- ◆ Pour the water over the child's head and into the garbage bag. The water should run through the bag and into the bucket.

Issues of privacy are important even to young children. They are very important to school-aged children and youth. We encourage you to keep this in mind as you plan for these daily routines.

If your child has any pain, movement during a bath may be uncomfortable. Giving pain medication ahead of time will make it easier for both of you.

Use only small amounts of mild soap/shampoo. It is hard to rinse thoroughly.

Mouth care

Encourage your child to brush her teeth at least twice a day for as long as possible. If she has trouble brushing, rinsing or spitting, you should do mouth care two to four times a day.

- * Raise the head of the bed to prevent choking.
- * Moisten and clean the tongue, lips and the inside of the mouth with a soft toothbrush. You can brush very gently.

OR

- * Clean and wet the mouth with a sponge toothette, or gauze on the end of a tongue depressor (popsicle stick) dipped in water or half strength mouthwash.

Tips:

- ♦ Apply petroleum jelly, lanolin, or lip balm to the lips throughout the day.
- ♦ If your child is able to swallow, give him small sips of fluid often.
- ♦ Use a dropper, moist swab, or spray bottle to keep the mouth wet through the day.

Talk to your health care professional if:

- * Mouth is sore or swollen.
- * Mouth has sores.

Skin care

Your child's skin needs special care because:

- * she will spend more time sitting, or in bed.
- * he may eat and drink less, so the skin will be less supple and healthy.
- * the illness/condition may cause skin problems like itchiness.

Problem areas: Bony parts such as hips, lower back, heels, elbows and behind the ears may need special attention.

* **Change your child's position often**

- ♦ *Give enough pain medication so your child will be able to move (or be moved) comfortably.*
- ♦ Use pillows to prop the body into changed but comfortable positions.

Keeping your child's mouth moist will help relieve thirst when she is not eating/drinking.

* **Keep the bed/chair as comfortable as you can**

- ◆ Keep the bed linens clean and wrinkle free.
- ◆ Use a foam (sometimes called an egg crate mattress) or water based or air mattress.
- ◆ Use sheepskins, heel protectors, and elbow protectors as needed. Ask your nurse whether a special mattress is available from any of the programs.

* **Keep the skin clean and dry**

- ◆ Don't use soap unless really necessary and then select a mild soap for bathing such as Ivory®, Neutrogena®, baby soap, Dove® or Alpha Keri®.
- ◆ Rinse all soap from the skin.
- ◆ Gently pat dry with a soft towel.

* **Apply lotion several times a day to bony areas or dry/flaking skin**

Good choices are: Cream/lotion containing Vitamin A & D or E, baby oil/cream/lotion, Aquaphor lotion®, Aloe vera® gel, Sween® cream/pericare cream, Hollister® skin conditioning cream.

* **Soothe itchiness**

- ◆ Bathe with cool water.
- ◆ Use oatmeal soap or one with oil.
- ◆ Add baking soda or small amount Alpha Keri® oil to bath water
- ◆ Put cool (not icy) damp, soft cloth over itchy areas.

If you can't control the itch, talk to your health care professional. There are creams, sprays, or medications to reduce the itch.

* **Take care of skin breakdowns early**

Watch for signs that the skin is breaking down

- ◆ redness;
- ◆ dryness, flaking, peeling;
- ◆ bleeding, blisters or openings in the skin;
 - itching
 - pain.

If you see a cut or sore or oozing area do not massage or use any lotion. Contact your health care professional to find out how to dress the wound.

Keep nails short and clean so scratching doesn't damage the skin.

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CANUCK PLACE CHILDREN'S HOSPICE

Parenting a Dying Child

Sleep

We can't do without sleep. Enough sleep is as much a concern for the caregiver as it is for the sick child. It is foolish to think that you can deprive yourself of sleep and continue to be the best you can for your child. Parents find that their sleep is linked to their child's sleep pattern. It is hard to be asleep when the child is awake. Keep in mind that other members of your family can take turns to be with your child so you have sleep time.

Sleep patterns change

Your child's sleep patterns will likely change. This is normal at the end of life.

- * **Sleep times may get shifted from night to day**

Some children fear the night and being alone while asleep. They fight sleep until they see the light of day, then relax into it. Some children nap for short periods at a time rather than having one long sleep. After the nap the child may have a time when he is very alert.

- * **Some children sleep much less**

They are afraid that they won't wake up, or that you will leave once they are asleep. Some children are not afraid, but use the time to think, come to terms and "ready themselves."

- * **Sleep may be more disturbed and restless**

- ◆ It may be filled with vivid dreams. Some dreams bring feelings of peace, others of terror.
- ◆ Night sweats or pain may wake the child.

- * **Most children will sleep more as death comes closer**

The child may be drowsy much of the time and have to work to stay awake, even for fun times. Some children will move into states of "waking sleep." They will seem neither fully awake nor truly asleep but are difficult to arouse. At the end, the child may slip from this into unconsciousness.

Consider how to respond to your child's changed sleep patterns

* If your child is not able to sleep or sleep is disturbed

Ask your child what might help:

- ◆ a night light and an open door;
- ◆ a bell beside the bed that she can ring if she wakes;
- ◆ moving his bed into a room closer to the centre of family activities;
- ◆ a massage, warm bath, or shower before bed;
- ◆ distractions like music, stories or videos;
- ◆ a hot water bottle inside a furry cover;
- ◆ someone resting on a bed beside him all night.
(Take turns with other family members.)

If the sleeplessness is distressing to your child, contact your health care professional to explore sleep medications, and other ideas.

Consider whether pain, night sweats or other physical discomfort may play a part in disturbed sleep. Ask for help with this from the health professionals.

* Make sure your child is safe in her bed so you can sleep restfully

- ◆ If he is in a hospital bed, keep the side rails up.
- ◆ If he is in a regular bed, install side rails if he is restless or confused. They are available at toy stores and pharmacies. They are easy to set up. You can also put the mattress on the floor.
- ◆ Pin or tie a small bell to your child's bed sheet. If he becomes restless or tries to get out of bed while you are resting, you will hear him.

* If your child is sleeping most of the time with very few alert times

- ◆ Try to gear family time around your child's waking and alert moments.
- ◆ Ask the doctor or nurse to review the medication to allow your child to be as present as possible for as long as possible.
- ◆ Respect the natural process of death.
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Try to sleep when your child sleeps. Allow close friends, family or volunteers to help you with chores like laundry, cooking, etc.

Fear may disturb sleep. Talk with your child about his fears. Be honest so that your child is truly free to share his fear. If you will not talk about death to your child, your child will carry his fear alone. (See the handout on Talking to the dying child and the "Emotional distress" section in this handout.)

Parent voice:

We really struggled to find a balance between staying connected in our usual way to Enrico and allowing him to fall into the long sleeps. All of us really wanted him to stay present with us. When he slept we felt we were losing out on our time together. Also, we didn't want him to feel we had given up on him as a member of the family. The other kids found it hard to know what to do if he was sleeping.

We suggested that they say good morning and good night and hello and goodbye in the usual way whether he was sleeping or not. We would still read a story and play music each day. We would tell him about friends and family who had called. But we gave up on the constant chatter and attempts to get his attention. We left him undisturbed by words and did more humming and handholding. It felt right but who really knows?

End note:

People say that we turn inward to our spiritual self, away from the activities of life, to prepare for death. We call this turning inward drowsiness, but perhaps it is a different state. Perhaps it is not one we can know until we come to the end of life. It is important to respect this state and not try to pull the child out of it. Perhaps this is the entranceway to peace?

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CANUCK PLACE
CHILDREN'S HOSPICE

Parenting a Dying Child

Loss of appetite

From the moment of birth, feeding becomes an important way for a parent to show love. For many, feeding their child is an act full of meaning. It represents caring for the health and life of the child. It represents giving pleasure or comfort to the child. But now, no amount of food will give life. You will need to think about food only in terms of the quality it adds or takes from the life. If feeding has been an important part of your parenting then changing your way of thinking about it will be hard for you.

We will all do the best we can to help your child take enough fluids and food to give the body what it needs at the time. But getting healthy children to eat a healthy diet can be a challenge. It is not worth the effort when there are no benefits for a child who feels sick and has very little energy to eat. Food becomes just another stress.

Parent voice:

My advice is let your child eat when and what he wants. Forget the Canada Food Guide!" P.S. The health professionals agree.

Signs that your child may not be enjoying food

- * complains that the food tastes "funny." Some drugs make food taste "tinny" or bitter or bad;
- * feels sick from the smell of many foods;
- * eats only one or two foods;
- * no longer wants even favourite foods or drinks;
- * finds chewing and swallowing too tiring after a mouthful or two;
- * chokes on food or drink;
- * children who are tube fed vomit or show signs of nausea. Their secretions may get thick, so breathing is noisy.

Consider how to respond to your child's loss of appetite

- * **Consider whether there is any treatment that might enable the child to enjoy food again.**

Sometimes we can treat the cause of loss of appetite – mouth sores, nausea, depression, certain medications etc. Sometimes we can't, and sometimes the treatment does not add to the quality of life.

Consult with health professionals about this.

Pushing food or tube feedings that your child doesn't want, or that make him uncomfortable, adds no value to his days.

Be clear to all members of the family that eating and drinking is not going to be a battlefield. Food and drink are for your child's pleasure or comfort. If they give no pleasure or comfort, then take them away.

An example of treatment that may help your child enjoy food again: if your child experiences nausea at mealtimes, give an anti-nausea medication 1/2 hour before the meal.

* **Think about ways to make food a pleasure and eating fun**

- ♦ Make a new rule: no more mealtimes. We eat whenever we feel like it. Have a bell beside your child's bed. Tell your child "ring the bell whenever you want to eat."
- ♦ Keep a number of small meals or snacks ready in the fridge. Make a menu and invite your child to choose from it.
- ♦ Keep a jug of juice and different sized glasses beside the bed. Pour a little juice into a huge glass sometimes and fill a doll's size cup at another time.
- ♦ Have a picnic on the bed.
- ♦ Keep a lunch box with snacks at hand to nibble on all day. (Remember that a child who is nibbling all day is less likely to eat a meal.)
- ♦ Try different temperatures for the food. Food may taste better at room temperature or cold.
- ♦ Be aware that the texture of food is as important as taste.
- ♦ Make pretty plates of food, green peas, red tomato, white rice. Draw a face on the boiled egg.
- ♦ Give a little food at a time so the child can feel good about eating it all.
- ♦ Offer food that is easy to swallow (if swallowing is hard) and easy to digest.

* **Consider food supplements**

Carnation Instant Breakfast®, Boost®, Ensure® or Pediasure®. These forms of food provide a lot in a small quantity. They may be good for a child who is hungry but has no energy to eat. The nurse or dietitian can help you decide which is best for your child.

* **Think carefully before putting your child on a diet or food that claims to cure**

Honest, well-meaning friends, as well as some dishonest people, may suggest special diets. It is hard to resist stories of miracle cures which come from a variety of diets low in one thing or high in another. If there were a diet shown to be an effective treatment, your doctor would know of it and use it. If you would like to try a special diet treatment, please discuss it with your doctor or nurse.

Avoid threats, bribes or rewards – all these are pressure tactics!

* **Prevent thirst when the child starts to refuse all fluids**

- ♦ Keep the mouth clean and moist. (Refer to the handout Personal care & hygiene). This will be the best way to provide relief if he is thirsty but cannot drink.
- ♦ Offer ice chips or a popsicle to suck.
- ♦ If you are worried about your child suffering dehydration call your doctor or nurse.

Be ready to tell when and how much fluid your child last had and when she last urinated.

Parent voice:

I was worried about Jen being thirsty because she couldn't swallow well enough to drink. It was good to know that just keeping her mouth wet with the toothette dipped in diluted juice was preventing thirst. And that was something we could all do for her to the very end.

Note: Many parents worry about thirst and dehydration. Keeping the mouth moist is as effective as drinking when a person is thirsty and approaching death.

* **Make a plan with the doctor or nurse for when your child is not willing to eat or drink.**

The body turns against food as a natural part of shutting down when it can no longer absorb or use it. Giving the food can cause pain and discomfort. It takes quality out of what is left of life. (See the handout Critical choices about feeding/fluids.)

Children who are tube fed may also become less able to absorb feeds. Instead of adding quality to their life, the feed will start to cause discomfort. You can try adjusting the feeds by diluting or reducing, as you may have in the past. You can talk with the doctor about medications or a change in formula. However, in the end stages of life your tube fed child will want less and less – maybe only a few mls an hour.

End note:

Remember to keep struggling against the idea that food will sustain life. Food can give pleasure; food can give pain. Concentrate on comfort, not calories, for your child. Trust the body to know what is best at this stage.

Never try to force food or drink on your child.

Parent voice:

I talked to some other families who were struggling with the food issue while we were in the hospice. Somehow it felt harder for me to stop the tube feeding than it was for other parents to accept food refusal from their children. I suppose the signs that the child really doesn't want it are less clear. I felt as if I was withholding rather than he was refusing. I felt a little better knowing that most dying people don't want food. When I skipped the feeds, I could tell myself that I was doing what he would have asked me to do, if he could.

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Parenting a Dying Child

Loss of movement

Some children are able to move around without help to the very end. Others lose muscle strength slowly but surely and need more and more help with things like feeding, getting on and off the toilet, or walking. Movement can also be affected by dizziness, fatigue, or paralysis caused by some conditions. It may also change the way your child is able to play and interact with others. Children can get very frustrated by these losses.

The team will do its best to find ways to support your child so that he can help himself for as long as possible.

Signs that your child may be losing the ability to move

- * slumps over often;
- * trips often;
- * needs support to keep balance;
- * gives up quickly on activities like combing hair or brushing teeth;
- * chooses to spend more and more time in bed.

Consider how to respond to your child's loss of movement

From your child's point of view, the loss is one of independence – what she could do before without your help she can no longer do. It may feel like being a baby. Losing what it means to be “grown up.” We will all try to manage this with sensitivity.

Ask family and friends to be helpful without commenting on the support they are giving. For example put drinks where they are easy to reach. Put telephone into the hand. Take the child's arm when walking.

Your child might ask questions about why he can't move like he used to. You can use these questions to try and find out what your child is thinking and feeling. (Refer to the handout “Emotional distress.”)

Parent voice:

For us the hardest was the day Jon could not stand for long enough to get from bed to chair. His knees seemed to give out and he crumpled up and fell. It was hardest because it was this that drove home to him that he was not getting better. He told us he felt like a baby that had to be carried. Other changes were less clear to him even though we could see them. Because he couldn't notice them, somehow they had less impact.

Parent voice:

I did not want to feed Jonah when he had been feeding himself for at least 2 years. I would bring the food already cut up, but arrange it as if this is how it was meant to be. This way I did not have to cut it up in front of him. I served soup in a small cup so he did not have to lift spoon after spoon.”

Parent voice:

Someone asked us what he could get Peter, our teenager. We suggested a speaker phone. Peter loved getting calls from his friends but he really could not hold the phone at his ear. This allowed him to speak in private. He loved that bit of independence.

* **Consider what kind of help would make it easier to get around**

As changes occur, your health care professionals can help you get equipment that will make moving easier and safer for your child. They can refer your child to an occupational therapist (OT). An OT can meet your child and advise on ways to make the most of the strength and movement your child has. Some examples of helpful equipment are a hospital bed, a wheelchair with head and neck support, bars installed near the toilet or shower/bath, or lifting equipment.

* **Consider how to protect your own back and muscles while helping your child**

- ♦ If you need to give your child a great deal of support when moving from bed to chair or toilet, make sure you know how to do these transfers without hurting yourself. An occupational therapist or nurse can teach you the safe ways to move your child.
- ♦ Ask for help when you can't manage safely on your own. Hurting your own knees or back is a danger you can avoid!

* **Consider ways to keep your child in on your family's activities**

- ♦ Some families move their child's bed into the living or dining room.
- ♦ Find things that the family can do that involve less moving around - watch movies, do a giant jigsaw, read books or listen to music together
- ♦ Have an inside picnic.
- ♦ Have a manicure night. Paint everyone's nails!

End note:

Movement is a very obvious sign of life - hurrying, moving about, doing. When we talk about things slowing down, we think about the pace of life changing as it moves to the end point of stillness.

Parent voice:

We rented a wheelchair as soon as it got hard to take walks. Pele enjoyed being out. The wheelchair made it possible for us to go on taking our evening stroll on the beach.

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Being with your child at the end of life's journey: knowing when death is near and how to ease the way with love

Dying is what happens as the body slows down in order to finally stop its work. It is the bridge between life and death. Dying is also readying the emotional self to let go. Your great gift to your child will be your calm presence as she prepares. We want you to know what to expect and helpful ways to respond during the final days and hours. In time you may be able to remember the last moments as a shared experience, as meaningful and dear as other significant spiritual times in your life.

Signs that the body is preparing for death:

Note: you may have seen some of these signs months before your child dies. The signs, themselves, do not necessarily mean death is close. However, these signs are almost always a part of dying.

* Sleeps more and is difficult to waken

Plan to talk to your child during those times when he seems most alert or awake. Even when your child is not sleeping he may seem withdrawn and "away." He may stare off into the distance. This is a normal part of letting go. Always speak softly and naturally even though there is no response. Never assume your child cannot hear; hearing is the last of the senses to be lost. Repeat the messages you want her to know into her last moments.

Hold or stroke his hand or cheek. Never shake an arm or shoulder in an effort to wake your child or pull him back to you. One way of "being with" your child in this "waking sleep" is to lie beside or sit close and breathe with your child. It will draw you together.

* Eats and drinks less and less

Offer spoonfuls of favourite foods and sips of drinks while your child is able to swallow. There is no point in coaxing food. Eating and digesting takes energy. The body will conserve its energy. A time will come when your child may hold food in the mouth but not swallow or refuse to have anything at all. This is a clear sign that you should stop feeding. You can still do mouth care to prevent thirst and dry mouth.

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To be a calm presence:

- ♦ Speak in a slow, low voice
- ♦ Relax your shoulders
- ♦ Slow and deepen your breathing
- ♦ Slow down your movements.

For several months or weeks, you may have seen changes in the way your child's body and mind is working. In the days or hours before death, the body and mind will wind down even more. Think about a clock that slows to a stop. For some children death comes more suddenly.

* **Breathing patterns change**

Your child's breathing may become irregular. A common pattern is shallow breaths with rests of 5 to 30 seconds and up to a full minute between. Or, you may hear your child panting and then breathing may slow down further and further with long breaks between. Saliva and mucous may collect at the back of the throat causing a gurgle/rattle. This is because your child cannot swallow. You may find this disturbing but it is not a sign that your child is in distress. Stay with your child rather than running to make telephone calls or set emergency systems going. Lift her head, or turn her onto her side so the secretions dribble out if you want to. Gently wipe the mouth with a soft towel. After death there may be a "final sigh" or sound from the throat.

* **Body cools**

Your child's hands and arms, feet and then legs will feel cool. The skin may look pale and/or mottled blue. This is a normal sign that more blood is going to the most vital organs and less to the limbs. Cover with a warm but light blanket. Don't use one that is electric or pile heavy coverings onto your child.

* **Bowel and bladder is less controlled**

You will notice that there will be less and less urine flow and it will get darker as it gets less. As death gets close, the muscles will begin to relax and your child may lose bladder and bowel control. You may want to use incontinence pads or diapers and pad the bed with a towel. Discuss with your health care professional. If you are at home, supplies may be available from the program supporting your child's care.

* **Restlessness**

Your child may appear agitated and restless, pulling at sheets or clothing. She may repeat a phrase many times. Don't try to stop this. Rather, be a calm presence by lightly stroking the head and humming. Some people suggest that you talk quietly about staying beside her. Let her know that you are ready now to let her go. Say goodbye, or whatever words seem right.

* **Confusion about people, time and place**

Your child may seem not to know even close family. This is hard to accept, but try not to insist and badger the child to recognize someone, even you. Just say who you are in a soft, clear voice. Keep giving messages of comfort and love. There are many ways to be known. Hearing is the last sense to shut down.

* **Vision-like experiences**

Dying people sometimes speak to, or about, something or someone not present for you. Accept what your child sees as there for him at this moment. Do not try to find out more or correct him. If your child seems frightened just comfort and say again that you are beside him and will not leave him alone. Leave a soft light on in the room.

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Parent voice:

We used singing and music to create calm for our child and ourselves. Music has always been a joy and comfort in our lives.

Preparing for the hour of death

Although you may be prepared for the dying, you may not be prepared for the death moments. It will help if you and your family can discuss what you want to happen at that time. These are some things to consider:

- * Who in the family wants to be present? Who will call them? (Keep a list of telephone numbers at hand.)
- * Who will take care of young children? What backup do you have if you can't reach them?
- * What about older siblings who choose not to be present. What is the plan?
- * What health professional will you call if you find, at the end, that you want a professional with you? What do you do if you cannot reach him?
- * Who will make the calls?

If you are in a hospital you can explain your plan to the staff. You can ask them to help you with the plan. For example, say if you want only your family in the room. Say when you want to hold your child in your arms. You can ask for your spiritual advisor to be called.

If you are at home and for any reason you cannot cope, call the ambulance. Make sure you give the DNR/DNAR form if you have one (see the handout [Critical choices about DNR/DNAR](#)). The ambulance will bring your child to the closest hospital. Do not try to bring her into the hospital yourself.

How will you know when death happens?

You will know your child has died when:

- ♦ there is no breath, no heartbeat;
- ♦ there may be a release of bowel and bladder;
- ♦ eyes do not move even if they are open;
- ♦ pupils are large;
- ♦ mouth falls open as the jaw relaxes.

Parent voice:

I can say quite honestly now, a few years after Megan's death, that no other experience has come close to the depth of feeling we shared as a family at the hour of Megan's death. It was as if we all felt the same common feeling – a feeling of wonder rather than fear. It was as if we were connected spirits. I can't describe it. I knew then what it meant to believe in a power greater than self.

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This kind of death is not an emergency. Therefore no one needs to leave the child to do emergency care. Still, not having to think about what to do, but being able to refer to a plan, is very comforting.

Having a plan is helpful no matter where you are when your child dies.

Parent voice:

One thing that made our lives easier in the end was that we had a contract with a funeral home signed before our son's death. We had made some preliminary decisions about what we wanted. We made these plans while we could still sort of think about things. We knew the 24 hour telephone number to call after the doctor had come. We had even selected and paid for a family plot. It was such a comfort to have these things in place.

In the hours after the death

Take the time you need to say goodbye:

- ♦ Call others whom you know would like to come.
- ♦ Some people have washed and dressed their child in special clothes. While brushing their child's hair they cut a lock of hair to keep. Some people want to make a footprint. You may or may not want a final photograph.
- ♦ You may want to create a sickness free space:
 - take all medicine, oxygen, IV lines and medical equipment out of the room;
 - bring in some flowers;
 - put on some music;
 - light a candle.

Parent voice:

We took all the tubes out. We washed and dressed Nicholas. I wrapped him in a blanket and held him. I held him without tubes. It felt right. He had never been left alone in his life. I didn't want him alone now. His brothers and sisters all passed him from arms to arms. Many people had known him in the hospital and many came to say their goodbyes. Housekeeping staff came and pediatricians came and all held him. It was the best decision I could make.

If your child dies at home

Some families will call soon to their family physician so that he can come to sign the death certificate. (It is helpful to know ahead who will do this and what to do if you cannot reach your doctor. The death certificate must be completed before your child is taken to the funeral home.) Others will want to call a spiritual advisor or a friend first. Again, it will be easier if you have a clear plan so everyone in the family knows what his or her part is in the plan. Everyone can then follow through without having to think about what to do. Make things as simple for yourselves as possible. For example write important telephone numbers on a sheet of paper. Put down even the numbers you know by heart. Keep the list close to the phone.

When your family has said their goodbyes, and is ready, call the funeral home. They will come and take care of the body and help you arrange the funeral. They will come in a regular car or van rather than a hearse. If you have no arrangements with a funeral home you can call at the time. Ask your doctor or nurse to help you with this. Refer to the handout [Honouring the spirit and caring for your child after death](#) for a guide to preparing funerals and services.

If you have traditions that surround the hours after death, let staff know how they can help.

Parent voice:

We took our time before calling the funeral home. We realized that this would be the last time we had Meg at home. We called her grandparents and aunts and let them know they could come and be with her one last time if they wanted.

There is no right or wrong in this situation. You may not want to spend time with your child after death. You may prefer to keep only the memory of the living child.

Call the doctor who will pronounce death and fill in the death certificate

If you cannot reach him, call the back up you have arranged. You can also call your nurse for help with this (even if you are in hospital or hospice, this will be taken care of for you).

Arrange for your child to be taken out of the house

There is no rush. When you are ready call the funeral home. They will probably come in an ordinary van rather than a hearse.

Telephone numbers you need right away:

Doctor to pronounce death:

Name: _____

Phone#: _____

Back up phone #: _____

Person to care for children:

Name: _____

Phone #: _____

Back up phone #: _____

Name: _____

Phone #: _____

Funeral home:

Name: _____

Phone #: _____

Spiritual leader:

Name: _____

Phone #: _____

Friends and family:

If your child dies in the hospital

When you are ready to go (this may be minutes or hours), the nurse will continue to take care of your child until he is moved to the morgue. If you want to see him again before he leaves the morgue, talk to the social worker or hospital chaplain.

When you leave the hospital take with you whatever is precious. No one can guarantee the safety of those things you leave with your child. You will have another chance to place them with your child later.

End note:

Grieving is yet another challenge. May you have the strength and courage to meet it.

Parent voice:

When Jess died the nurse helped me bathe him. I brushed his hair and dressed him for the last time. I wish I had left after that. Being there while they put ID tags on him and wrapped him in a sheet are not helpful memories. Some things are not part of a parent's care. I think they are better left to the professionals.

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CANUCK PLACE
CHILDREN'S HOSPICE

Talking about death

Talking to the dying child about death

No one can tell you what to say to a child about dying. No one can write such a script. It is so much easier not to speak, to pretend that we can protect our child from more pain. We ask ourselves why we should add fear to our child's burden.

But research shows that a child whose condition is getting worse almost always knows that something is very wrong. The child, like you, may pretend not to know because he wants to protect you. Both of you are pretending, both of you are protecting, both of you know something serious is happening.

However, research tells us about children, it does not tell us about **your** child in particular. It cannot tell us about your family. You will choose how and what to say. This is just a guide. It may not fit with your understanding of what is best for your child.

Listen very carefully to your child's comments and questions

Follow your child's lead but know where your response is taking the conversation.

For example: *"Will I get better?"*

- * If you answer *"we'll have to wait and see,"* you will lose some of your chance to talk about it, and miss a chance to give support.
- * If you answer *"sometimes no matter how hard everyone tries, the body can't be fixed."* You leave an opening for your child to ask more or not. (Not all children choose to move ahead right then)
- * If you answer *"no one knows for sure but what do you think about that,"* it allows you to get a sense of what your child is thinking.
- * If you answer *"Sounds like you want to talk about what might happen if you can't get better – do you?"* it will lead right into a discussion.

If you answer *"I've been thinking about it too. Shall we ask the doctor to talk to us about that?"* It allows you to delay dealing with this until you can get some support from a health professional.

Opening the way to a discussion of death allows your child to share her fears. None of us wants to leave a child alone with fears. So we must try to be brave and honest and open in order to give comfort.

Listen for hints that your child wants to talk. Your child needs to know that you are willing to listen, and, that what you say can be trusted. If you never mention the child's illness and the changes in her life, you never give permission for them to be discussed.

Consider talking about death as a process rather than a one time event

- * You may need to give many chances for this conversation. Not every child will ask about death, but every child needs at least a few times when she knows you are ready to hear and answer.
- * Once you have an opening moment, think about your response as taking the first step. You may go only a short way in the first talk, or, your child may prompt you to keep going. You may need to go back over the same ground many times in different ways. These talks can be times when you draw very close to your child, quiet his fears, and explain that what he means to you will not change, whatever happens.
- * Not every child will ask the questions that will allow the conversation to happen. You may need to find different ways for a child to express herself. The child's drawings, stories and play may offer chances to talk about dying in a softer way. You can draw attention to a tree blossoming and talk about life cycles, or clouds that come and go, without moving into any mention of the child's condition at first.

Talk so your child can understand

Children can't understand abstract ideas until they reach their teens. They think in terms of what they can know with their senses. Heaven is a place like the world, God is a person, and so on. A concept of a "soul" may be hard for a child to grasp.

- * Try to match what you say to the real things your child has seen or done.
- * Use simple words and sentences.
- * Be honest and to the point.
- * Manage your child's questions and concerns.
 - ◆ If your child is anxious about the process of dying:
"Does it hurt to die?"
Reassure that doctors and nurses can make things feel comfortable even if they can't make the body well. Ask your child if she wonders about how dying feels. Wait for a response. "*Some parts of the body will work more slowly so you may feel tired and sleepy. You may not want to eat. You may sometimes think you are floating or inside a dream.*"

Children are more likely to ask hard questions if you are open with them and don't change the subject when sad topics come up. If you talk to them about serious things children learn to talk to you in the same way.

These discussions can be very meaningful times with your child. Treat them as precious moments rather than ones you dread. If you have thought about ways to talk with your child, you will be better able to respond with grace. You can prepare yourself by reading some things about a child's understanding of death, by talking to a member of staff, or by talking with your partner about what you want to say.

Being alone is a great fear of most children. Say often and in many ways that you will be with your child when he needs you. He will not be alone. "When you are very tired you can close your eyes and float as if you are resting on a cloud because I will still be here. You will hear my voice."

Parent voice:

I asked my 16 year old how she pictured her death. Her response was wonderful.

She said, "I will either be at Canuck Place (the hospice in which we spent time), with all of you dear people around me, or I will be an old lady on the porch of my house. I will be watching the sun go down with my husband in a rocking chair beside me.

- ♦ If your child asks direct questions about death and beyond "what will happen after I die," you will need to reach into yourself to share your spiritual beliefs with your child.

Parent voice:

I am not a believer in a God or an afterlife so I just didn't know how I was going to answer those kinds of questions. I knew I wasn't going to pretend something I didn't believe. Strangely, the hospital chaplain was really a help. She made me realize that I did believe in a love that existed now between me and my child and would not die. It would remain with me and be part of my life. That love would be a presence in every memory. It would go nowhere. It would stay right here with me. So when the question about life after death came I answered my truth, 'You will go back to where you started – as a feeling of great love inside me.' Of course I had to try to make that idea something a ten year old could understand. I asked several friends to help me with this idea. I came up with images 'like a song that stays in my head', that is what you will become. Another time I suggested that she could become part of me, sharing my life because even now, when we were apart she remained always with me in my mind rather than on my lap.

Spiritual beliefs are not tied to religious beliefs. Here is your chance to also tell your child about your love and the power of memory.

Do tell your child how she will always remain part of the family. You can say something like: "From the very first moment I saw you after you were born, I loved you. We called you - (Name) -You became part of our family. (Name) will always be part of our family. As soon as I think your name you come into my mind - always. When you are at a sleep-over, or in the garden, you are still in my mind and heart. When I look at you here, or your picture on the wall or, the picture in my mind I feel the same love for you. When I think of you I feel that you love me too."

- ◆ Some children, even after serious conversations about death, may talk cheerfully about the future. This stumps many parents. What can one say to “*when I grow up I want to be /do?*” It is not easy to understand what the statement means. It may mean that the child is expressing a simple wish about the future. It may be a roundabout way for the child to ask about what the future looks like when life ends. It may be that the child is not ready to accept what he knows. One response might be to ask “*Do you want to play a story game about being grown up? Let’s think about (or find out about) what it is like to be a fireman.*” By talking about the future in this way, you can go along side the child with honesty.
- ◆ Children sometimes ask the “why me?” question. This is when you might have to answer with the only truth: “*I don’t know. No one knows. It is just not fair that you are sick. No one, not you, or me, or anyone did anything to make it happen.*”
- ◆ Your child may worry about what will happen to her family, pets, even things, when she is gone. If your child wants it, you can involve him in thinking this through. “*We are all going to be sad even if we keep you close in our memories. What shall we try to do to make us less sad? What would you like me to do with your special things? You can think about it and tell me when you have an idea.*”

Be ready to manage your child’s reactions to talking about death

You and your child may feel a sense of closeness and the comfort of having shared feelings that were not allowed up to now. It is also possible that either of you could feel terrible grief. Grief can show itself as rage or deep distress. Hold your child through it so he feels your sympathy and abiding love. After a time, do some activity to bring him back to a more even emotional state. You can read a story or watch a videotape together. The message of this is that there is still a life to live.

End note:

Sometimes it is just too hard for a parent to talk about death with the child. There are people on the health care team who can help. The chaplain, social worker, a nurse or doctor can be your partner in this. You may need their support, especially with youths, who may be caught in complex feelings like anger about their fate, a desire to protect their parents, or a rebellion against the choices others are making for them.

Parent voice:

I was dreading the conversation about death. I had to plan it with help from the nurse and some books. I rehearsed it in my mind. I started by reading the book Water bugs and Dragonflies one evening. It went so much better than I had thought possible. It brought us closer. I don’t regret any of the talks we had. We had quite a few about death in the last weeks.

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Talking with siblings

Your other children will sense your great distress and will be anxious for all the family. Most parents realise this and try to give everyone the love and comfort they deserve. Finding the energy for siblings' needs may be very hard but it is important.

Just as you listen for signs that the dying child wants to talk about the dying, listen for these same questions and signs from the siblings.

In summary:

- ♦ answer questions about the illness or dying simply and honestly. Don't burden children with details.
- ♦ Try not to confuse with terms like "losing her" or "being taken from us".
- ♦ It is better to use clear words like "body is so sick that it can't work well anymore. If it stops working then —will die."
- ♦ Not all children can express their feelings or questions with words. Use play and drawing and storybooks as a "way in."

Be prepared to open the topic yourself if the siblings do not ever mention their worries about their sick brother or sister

This script is a guide. Adapt it or create one that works better for your children. Remember that the health care professionals are very willing to help you if you need them.

"The doctors are finding it very hard to help _____. There are parts of her body that are not able to work anymore no matter what medications or treatment we give. It seems that her body is getting ready to die. None of us can help what is happening in her body. What we can all do to help is make our time together as a family the best it can be. We can try to enjoy each other, help each other, and show our love and caring for each other."

Consider whether a sibling's behaviour might be reflecting emotional stress

(It will be useful to read the section on "Emotional Distress" in the handout [Parenting a dying child](#).)

Sibling voice:

When my brother was sick, I felt lonely. Everyone was sad and tired all the time. I had to do things on my own or with other kids' families. I felt like I wasn't important in my own family anymore.

Many of the suggestions we offered around talking with the dying child, also apply to siblings. It may help to review them.

Not all difficult behaviours can be explained as stress from the illness of the sibling. This is only one part of life. There are many other stresses in children's lives. But you should take account of the special stresses of the illness.

* **Defiance** may be:

- ♦ A way of getting **attention** from, or punishing, a parent who has withdrawn.
- ♦ An effort to get oneself punished in order to deal with **guilt**. There are some children who think that they might have caused their brother's condition by their thoughts or actions. Their thinking might go something like, *"I wished a bad thing would happen and it has come true. It's too risky to admit this but I do need to be punished."*
- ♦ Taking advantage of lack of firm limits from parents who feel that they "have to allow more in this time of stress." (Think about the limits you set on behaviour as being a safety fence. Taking it down leaves the child insecure. But you may want to extend boundary lines a little at this time.)

* **Denial**. The sibling may refuse to talk about or listen to you talk about her sick sibling. She may do nothing to help and even stay away from her. This is fairly common among youth who keep their feelings to themselves. Denial may be quite hurtful to parents and to the sick child. It looks like the child does not care because she lives as if nothing has changed in the life of the family. It is important to try to help this sibling find a way to participate so she can share some precious moments. It is just as important not to force the child to face up to this great sorrow. Some children can cope in no other way than by turning away.

* **Angry outbursts**. These may be:

- ♦ A build up of resentment against parents, the sick child, or the world in general.
- ♦ A build up of tensions held onto inside that then explode in tantrums. It is not unusual for a young child to be angry with the sick child. This is upsetting for you, but try to be understanding. You can respond by reflecting the feeling, *"You're angry are you? I feel angry too quite a lot. I know it doesn't feel good around here some days. It is OK to let the anger out, but not with hurting your sister. Let's think about how else you can let it out."*
- ♦ The anger may switch to love after the "vent" and then anger again. Young children move easily from one feeling to another. They may feel bad, mad or sad and ten minutes later want to go out to play with friends. This is normal and healthy.

Because of normal sibling rivalry, a child in the family may feel he is to blame.

One child said, *"I really got scared when my parents stopped caring about how I behaved!"*

Siblings may need some help from an adult friend or a counselor. Ask a healthcare professional for advice setting this up.

A young adult looking back on this time said, *"I remember feeling how unfair it was that no one paid any attention to me. I felt as if I didn't count."*

- * **Cries a lot, hangs around doing nothing, shows no interest in school, friends and activities.**

This may be loneliness, sadness or even depression.

- ◆ Try to include the siblings in the care of the child without insisting on it. Suggest some things he can do for the sick child. Even very young children can help. *“Can you be the one who makes sure your sister’s teddy is on her bed? Can you read a story each day? Can you keep the glass full of juice?”*
- ◆ Connect to your other children’s lives. Take a short time each day to ask about something important to them, *“How did you do on the test? Did you have fun at the party?”* Taking an interest in the concerns of your other children shows that as you give love to the child whose life is ending, you do not withdraw from the child whose life goes on.
- ◆ Try hard to play and have some fun as a family. This is to allow your other children to be children. It will help them be generous and loving to the sick child. This does not mean you put on a false happy face. It just means that you show that in the midst of great sadness there can be times of joy. Joy is not wrong.

- * **Worries a lot, can’t sleep, clings and acts less grown up than you expect.**

- ◆ Children may feel very insecure. Life is “on hold.” The routines that gave a sense of security may all have changed.
- ◆ There may be bickering, crying, anger, silences between parents who, before this, were strong and in control of things. It is disturbing for a child to witness a parent’s despair. It is helpful if you can explain what your child is seeing. For example: *“This is a hard time for all of us. I am upset because we are not able to make - better. When I am crying it isn’t you who has made me sad. When I am angry it is not at you. I love you and - very much. It is O.K. to feel all these feelings and to show them. We can give each other hugs to show we care. I will come and ask for a hug when I need one. You can ask too.”*

“Daddy and I shouted at each other because we were tired. We didn’t try hard enough to speak nicely. We will feel better after we have a rest. Can you read quietly in your room while we sort out our problem?”

Sometimes it seems to a sibling that the only things that get any attention are the concerns of the sick child.

Make sure the siblings know that it is OK for them to continue their sports and other fun activities. These may be key outlets that support their ability to cope with the stress in the home.

- ◆ Fear may take the form of worrying about his own health or that of the parents. You can reassure your child that most people do not die from their sicknesses. They get better. Most people live a very long time.
- ◆ Death, because it is so hard to understand, can be imagined in fearful forms. (See the reference list for some resources for explaining death to children of different ages.)

School

School age children spend many hours at school. It may be the place where siblings have a period of distraction from home concerns. It may be the easiest part of the day for them. School is also sometimes a real pressure for the siblings who are tense and fearful and not able to focus attention on their work. They may slip behind or develop behaviour problems. We suggest you talk with your child's teacher and/or school counsellor so that he can offer support and understanding.

End note:

You are a person, not a saint, so forgive yourself when you can't be the ideal parent we write about here.

Allow your grief - sadness, anger, frustration - to show, not all the time, but enough. This permits your children to accept their own feelings. A parent who is under control at all times suggests that the children should be this way too.

"Daddy has a pain – will he die too?" "I am sick, maybe I won't get better". Young children will need reassurance that this will not happen to them or to you.

Just keep talking to your children about feelings, including how much you love and care for them. Show this in whatever way you can.

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Talking with family and friends

Family and friends are part of all big life events and passages. They can be a great comfort and support. Some are better at it than others. Sometimes family and friends disappear when you would like them to be there. At times they are too much involved. They may make you sad or mad when they say the wrong things. Not everyone will know how to behave with you or your child. Some people feel helpless and afraid.

Family & friends may not know how to give emotional support

You can't do this alone and really, people want to support you. When they are clumsy it is because they don't know what to say or do. It is sad, but true, that how you talk to others about your child can make a difference in the emotional support you get.

The scripts below, like those in other sections, are just ideas to start you thinking.

* When you are asked about your child

You can say honestly that:

“ _____’s condition is getting worse There seems little anyone can do to improve her condition. We are focussing our attention now on giving as much quality as we can to the rest of her life. We have decided to... Our plans are...”

You may not want to answer questions about your child. It is O.K. to say: *“Thanks for asking but I don't want to talk about it now.”*

* If family or friends challenge your decisions

You can say something like:

“It will help me most if you accept what I say and can support us in what we are doing.”

You may not want to have to give the same hard message over and over. You can ask a family member or friend to be the contact person for your family. Let it be known that anyone can call that person for updates.

* **If people give unwanted advice about what you should do**

You can say:

“I know you care about me. Thank you for that. I don’t have energy for “shoulds”. I am doing what I can and what we feel is best”.

Or, “Thank you for caring. You have been great. Remember, though, we are at the bedside all of everyday. We talk to the health team all the time. We trust them and are quite sure we are doing what is best. It just adds to our stress to feel that you don’t trust our judgement.”

* **If people are strained with you**

- ◆ People often feel that they mustn’t show emotions. They want to cry but stop themselves. They are about to tell you something funny but stop themselves. Explain how you feel about this. Most people are afraid to upset you:

“Don’t stop your tears. It allows me to cry with you... and don’t feel that you have to say some magic words to make me feel better – there aren’t any. We can just cry and hug each other.”

“I don’t want you to stop yourself from telling me funny stories. We always laugh together. A laugh is as healing as a cry.”

“ Please don’t avoid mentioning _____, you know it helps me to talk about _____ and her friends. Please let’s do that.”

- ◆ Sometimes friends and family disappear if they think they have upset you by saying the wrong thing. Reassure that you feel comforted and supported by them. *“I know my crying made you feel bad. I just want you to know, I cried because you made me feel comfortable enough to do it. Thanks for your visit.”*

Friends and family will certainly want to help

Let them help – it makes them feel a whole lot better.

They will ask about things they can do for you. The more help you get, the easier it is to be your best for your children.

* **Keep a list of specific things people can do that will be helpful.**

If you have a contact person give her the list too so she can make suggestions. For example:

- ◆ Please can you do my grocery shop this week? I will have a list for you.
- ◆ Please can you cut the grass.
- ◆ Please take my other kids to see the movie all the other kids are going to see.
- ◆ Could you be here for a few hours so I can go and get school supplies for my other kids?
- ◆ Can you take my son to soccer each week when you go.
- ◆ Can you find a tactful way to tell my sister I don't want her to talk about God's role in this when she visits?
- ◆ It would be lovely to have a batch of homemade cookies.
- ◆ Bring dinner and join us on Thursday – it would be so nice to have an evening with our good friends.
- ◆ Please help me organize a birthday party for

* **Guidelines for asking for help:**

- ◆ You don't have to explain why you need what you are asking for.
- ◆ Give a few options from which people can choose.
- ◆ Be specific and give clear instructions, e.g., "keep the dog on the leash, even in the open field".
- ◆ Try to ask people for something they can do. Aunt J. may be useless at childminding, but wonderful on casseroles.
- ◆ Be ready for some people to say no when you ask. This has something to do with their life rather than with you.

* **Be aware that you may be expecting more than some members of your family can give**

- ◆ If you don't usually talk about feelings in your family, you may not be able to share important things now.
- ◆ When we are on edge and needy we want those closest to understand and support us. This understanding may not happen, even between close partners.

Parent Voice:

Every time my partner (my sick child's stepfather) saw me cry he would say the same thing 'What? What's it now?' So what was it now? It wasn't what was now. It was what was yesterday and the day before and forever. I just had to accept that he couldn't help with talk or touch when I was upset. He was showing his love and support by taking over all the household chores, carpools and pet care. He did this without me asking it of him. That was what he could do, and he did it, every day for two months. But it took a friend to point this out to me!

End note:

Keep talking to family and friends so that they learn how to support you. But don't judge others badly if they just can't be there in the way you want them to. So few people can do this just right! You may all have to love each other and forgive each other as best you can.

Some people do not cope at all well with stress. They are not at their best when you need them most.

Try not to judge those you love too harshly. "If he really cared for me he would know" He may really care for you and still not know when you need holding or when you need to be alone.

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Talking to classmates and friends

When children are old enough to attend school, they are old enough to have friends. The more their minds and emotions develop, the more important friends become. By the time children are teenagers, friends are the most important people in their lives. If the illness has been a long one, or the condition has seriously delayed development, friends may be less important than family. Still, if your child has been part of a regular school class, he will be missed. School mates will be concerned about their friend.

The school teacher will appreciate a call from you telling her about your child. When you make this call you can tell the teacher what information you, and your child, want her to give the class. You may feel able to connect with close friends of your child yourself. Some people ask the best friend or, for young children, his parents, to call the other friends. You can also give this job to someone who asks “can I do something for you?”.

Ideas for what the teacher can say:

- * *“ — is very sick. She is not able to come back to school or have visitors. We can help her by... I don't know anything more I can tell you. When her family has more information for us they will let us know.”*
- * *“Everyone at the hospital has tried very hard to help — get well. — has taken lots of medicine and had lots of treatment. Almost all people who get sick get better. Sometimes there is not a way to make someone better. — may not get better.”*
- * *“She is still very sick and we don't know if she can get well again. She wants you to know that she thinks of you. She would love it if you (phoned) or (wrote a card) or (visited). The best times are...”*
- * *“His body is becoming weaker. He is not able to get out of bed/leave home/come to school. We are not sure he will recover.”*
- * *“His body can no longer work well; he may die soon.”*
- * *“Her lungs/kidneys/heart is getting weaker because — has a (disease/condition) called —. This is not the kind of sickness/condition you catch. — It is caused by Her body may get too weak to go on working. She may die.”*

The students will probably ask the teacher more questions about your child's medical condition. Say if you are comfortable with her telling the children more. Make sure she explains that this is not something one can catch from others. If you prefer, you can give her the name of a health professional to contact for an explanation of the condition. You can, of course, ask the teacher not to give out any information from the school until you are ready.

If your child is part of a smaller group - soccer team or scouts - you may want to draft a letter to send to the group. There is a sample you can modify in this section. You can also ask one parent to let others know. Be specific about what you want him to say. Give this parent some suggestions of things the group can do for you or your child if they ask about this. For example:

- ♦ Make a photo album with pictures of each child and the group together. This can be a wonderful way for your child to relive happy times. It lets her know she remains part of the history of the group. It is a healing activity for the children who do it.
- ♦ Make a videotape of the group sending messages to your child.
- ♦ Make a giant card.

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Sample letter

Dear friends of ———

We know that you have all been concerned about ———. Thank you for your *(name what the group may have done cards, calls, gifts etc)*. — was so pleased to hear from you. This is what has happened. The sickness/condition *(name it)* that — has is now weakening his body. The doctors and nurses are still trying to fix things but the medications and *(name other treatments)* are not working too well. We hope very much that — will be well, but we understand that she may get so weak that her body will die. We don't want — to go on getting needle pokes or medicine if they are doing no good. Her life may be short and we want it to be as good as we can make it. We have decided to

(bring her back home so we can all be together)

(move out of the hospital into a more homey place where there are nurses to help care for her)

(stop any treatment that is uncomfortable and does no good).

If any of you want to send messages to — here is how you can do it. *(fill in)*

If you want to find out how she is doing you can call *(fill in)*

OR

Our family is sad; it is hard to talk to lots of people on the phone so we would prefer if you wrote notes rather than called. We will let you know through *(put in a name)* if we have other things to tell you.

Honouring the spirit and caring for your child after death

If you have used these handouts as your guide, it means that for most of you, the dying has taken weeks or months or at least days. But no one is ever prepared for the death itself. Death and birth are peaks of human experience. Nothing else in life comes close enough for us to prepare for them. For preparing ourselves means relating them to something similar. Unless you have been this close to someone before, and been with him at the dying, you cannot really be ready for your response.

In the days right after the death you will have a lot of decisions to make and things to do. The following pamphlets may help you with the plans for what you wish done with your child's body. They are available from the Family Resource Library at BC Children's Hospital or from a health care professional.

- ♦ Autopsy
- ♦ After the Death: Burial, Cremation, Funeral, Memorial
- ♦ Organ donation

What we would like to offer in the rest of this handout are some thoughts on ways of honouring the spirit of your child and helping to make and shape memories.

Death and birth are peaks of
human experience

"Eternal presence, glancing
light, does not depend on
touch or sight".
(Errol Durbach)

In the days after the death

Plan any ceremonies you want

You may want one, more than one, or none. These decisions are often guided by traditions, but what you choose should reflect what you hope the ceremony will do for you and the family.

Some answers may be:

- ♦ a chance to draw everyone together whose life was touched by our child, to say farewell and draw comfort from each other
- ♦ to make an occasion to hold as a memory that we can look back on
- ♦ to share the joy that our child brought to our life and the lives of others
- ♦ to fulfill a religious ritual

It is useful to consider the costs involved and keep this in mind when you make decisions. Some costs are indicated in the pamphlet “After the Death: Burial, Cremation, Funeral, Memorial”.

* Organize the event

What will it be (a memorial, a funeral, a celebration of life)?

What shape will it take (a joy-filled celebration, a sacred happening, a religious ritual)?

When will it be?

Where will it be?

Ceremonies are for the living. Talk with those closest to you around the question, “What is this ceremony for?”

Some people have decided to have just a small family event after the death and then on the anniversary of the death or on the birthday, to have a larger public event to celebrate the life.

If you are choosing a ceremony at a church, synagogue or temple, the religious leader or funeral director will help you with the planning.

Make sure you have left enough time for people who might like to come from further away.

Check that the place is available.

Who will conduct the ceremony?

What will be included in the ceremony?

Some ideas:

- ◆ Prayers – the hospital chaplain or your own spiritual leader will help you with a selection.
- ◆ Music - consider what your child might have liked, or music that creates a mood you want or songs with words that are meaningful to you.
- ◆ Readings - ask a hospital chaplain or a librarian to help you find a book of suitable readings if you like the idea but nothing comes to your mind.
- ◆ Memories from people at the ceremony – this can be an invitation to speak at the moment or you can ask people to give written cards to be read.
- ◆ A silent time.
- ◆ Slides or a video set to music.

What things do you want to have in the room?

- ◆ Photos
- ◆ Flowers
- ◆ Awards
- ◆ Letters
- ◆ Candles
- ◆ Special toys, badges or other objects with special meaning.

Who will help with what?

Parent voice:

We made a memory board using photos and items that reminded us of Mark. We had his friends cut and paste the items into a collage.

Who will be invited and how will that happen?
(Use a separate sheet to make a list of those you want to ask.)

Parent voice:

I kept a notebook with the names of those people who contacted us about Mandeep in his last months. I asked my brother to call all of them to tell them about the death.

* Consider how to involve children in a ceremony

Try to involve the children in some ritual that they will understand. Some ideas:

- ◆ letting go of balloons on which your child's name is written
- ◆ planting a flower box with each child adding a small plant that will bloom each year
- ◆ having each child light a candle to stand in a container
- ◆ asking each child to bring a bead in a colour that makes him think of your child. Making a necklace with the beads that will hang around a photograph. (This can then also become part of a memory box.)
- ◆ asking each child to bring something to include in a memory box
- ◆ asking a school choir to sing a song at the ceremony
- ◆ suggesting that a few children write a letter to your child that can be read at the ceremony.

* You may want to have a eulogy as part of the ceremony

Many people find public speaking hard to do even at the best of times. But you or someone in your family may really want to do the eulogy. It may be the hardest speech you will ever give. It will not be one you regret. It can help you draw the many things you loved about your child into a memory pattern that you and others can hold onto.

Parent voice:

I wanted to create the eulogy but I did not feel sure that I could speak it at the ceremony. I asked my sister to read my eulogy. I got this idea from another funeral I attended. The father began the eulogy for his son but when his emotions overcame him, his brother stepped forward and read the rest of it. The brother was clearly prepared ahead of time to read if he needed to.

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You can ask one of your friends or family to do a phone tree.

Including siblings and the child's friends in a ceremony can help them with their sadness.

A eulogy is a sharing, with words, of the blessing of the child's life.

A eulogy need not be a masterpiece. Honest memories are all that is needed.

Some ideas on how to create a eulogy

- ◆ Gather your thoughts about the essence of this child and note each in point form.
- ◆ Write down the high points in your child's life (even a small baby will have some of these – his cry, her eye).
- ◆ Decide on a format or theme for the eulogy.

Some ideas:

- It could be a letter to those whom you want to care for her spirit. The theme could be an introduction to the child.
- *“Dear ones who are caring for the spirit of my child. I would like you to know these things about this special person...”*
- It could be a summary of how you came to understand the nature of this special child.
- *“Friends – Some say they understood their child from the first. Not I. I grew in understanding throughout the ten years of her life. My first thought on hearing her birth cry was*”
- You could start by thinking about your feelings when you first saw her and go on to describe all the other “first times.” First day at daycare, first birthday, first time she lost a board game, first words, first time she made you angry, etc.
- You could talk about your child in terms of the “colours” of her rainbow personality.
- You could just do what a great poet (Elizabeth Barrett Browning) did and say “How do I love thee? Let me count the ways” and take it from there.
- You could quote from some of the cards you have received.
- Organize your thoughts from the cards into the format.

You can write each point onto a card and then number your cards. Or write it into a computer.

Use large type and separate your paragraphs with lots of space so it is easy to read.

- ◆ Give special thought to the ending.

Quotes from a book that was meaningful to your child may turn up something wonderful. Look to some of the wise people who have written of life, death and the human spirit for verses or passages that speak to the heart. A hospital chaplain whom you know, a librarian or your spiritual leader may be able to help you find something suitable.

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Keep it short and simple so that, even though you may read from your notes, you sound as if you are speaking to friends rather than reading an essay.

- ◆ Rehearse: read it out loud several times. Highlight the main points with a yellow marker.

Give a copy to your “back up person” so he is familiar with it. Make sure he knows the correct way to pronounce any names.

* Consider tributes

- ◆ Decide about the form of tributes

Many people will want to offer something to honour the spirit of your child. You may choose to let them do it in whatever way they choose or, you can suggest a way, such as the following:

“If you would like to honour Jason:

- *please send a donation to —; or*
- *“we would love to fill the church with flowers”; or*
- *“we are setting up a scholarship fund in his name”. Contributions can be made to ———*

- ◆ Decide how to inform people of your wishes

The simplest way is to include your wishes in an obituary notice if you are going to make one. You can also tell the friends, who will be calling to inform people of the service, about your wishes. You can ask the person conducting the service to make mention of this. You can make a little notice to put on a table at the place of the service.

In the weeks and months after the death

Having supported your child through “the valley of the shadow of death,” you will now begin to climb the mountain of grief so that you can come again into the easier fields of life. If it is not part of your package, please ask the health professional or funeral home for the booklet called “Finding your way: grieving the death of your child” or some other helpful materials. (See also the resource list handout and Griefworks BC website: www.griefworksbc.com).

Parent voice:

In our family we all have a copy of Dad's eulogy to Molly. We all read it on the anniversary of her death when we light a candle for her. It marks the day and holds us in a common memory, as a family, wherever we are in the world.

Parent voice:

I made a memory book in the week after the death. I pasted in the pictures I had taken and wrote captions beneath them. I made a note of Brynne's favourite songs, books, foods. It is funny how we forget things we figured would never leave our memory – like the name of the book we read to him so many times, the song we sang together the day before he died. It was a healing activity at the time and I am so glad to have it now.

There is a message about grief that says much about what has been, and what lies in the future:

“Tears water our growth.”

We wish you the courage to grow.

This pamphlet is the result of a collaboration between
British Columbia's Children's Hospital
and
Canuck Place Children's Hospice

Information about ordering copies:
online: www.cw.bc.ca/library/bookstore

email: famreslib@cw.bc.ca

Phone: 1-800-331-1533

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Resources

This list is by no means complete. It is meant as a starting point for you.

Websites:

- * www.griefworksbc.com – this local site contains extensive resource lists for children, teens, and adults
- * www.palliative.info – a Canadian site that provides links to many other web resources
- * <http://www.journeyofhearts.org/jofh> – designed as a place for resources and support to help those in the grief process
- * <http://childendoflifecare.org> – this site, designed for health care professionals, covers all aspects of caring for children and families when a child is dying

Books for adults:

- * Care of the Dying Child
Robert Buckingham
- * When Your Child has a Life threatening Illness
Thomas T. Frantz
- * Adolescence and Death
McNeil and Corr
- * Talking about Death: A Dialogue Between Parent & Child
Earl A. Grollman

Books for adults to read with their children:

- * About Dying: An Open Family Book for Parents and Children Together
Sara Bonnett Stein and Dick Fran
- * For Those who Live: Helping Children Cope with the Death of a Brother or Sister
Kathy LaTour

Books for adults to read with their children cont'd...

- * Unspoken Grief: Coping with Childhood Sibling Loss
Helen Rosen
- * What About Me? When Brothers and Sisters Get Sick
(siblings, 4-8 yrs)
Allan Peterkin
- * Waterbugs and Dragonflies
Doris Stickney
- * Kid's Book about Death and Dying (3-5 yrs)
E. Rofes
- * Gentle Willow: A Story for Children About Dying (4-8 yrs)
Joyce C. Mills
- * When Dinosaurs Die: A Guide to Understanding Death
Laurie Krasny Brown and Marc Brown
- * Lifetimes
Bryan Mellonie and Robert Ingpen
- * The Fall of Freddie the Leaf: A Story of Life for All Ages
Leo Buscaglia
- * Little Tree: A Story for Children with Serious Medical Problems (6-12 yrs)
Joyce C. Mills
- * Help for the Hard Times: Getting Through Loss (youth)
Earl Hipp
- * The Next Place
Warren Hanson

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