

## Wear and tear

No matter what kind of family you have—large, or small, two-parent, single parent, foster parent, or step-parent, your family will be affected by your child’s CHD. There will be many emotional ups and downs. Events such as your child’s diagnosis, major tests, surgery, a stay in the Intensive Care Unit, coming home from the hospital, starting school, and moving from pediatric to adult care can all be stressful for the family.

**S**ometimes it will seem like everything happens at once—there may be a new baby in the family, a job change, a move to a new place, at the same time your child is in a health crisis. These stresses add up and can make coping with day to day living a challenge.

Much of your family’s energy will be used in supporting your child, dealing with doctors, going to the hospital, and keeping the household going. When your focus is on a sick child, your other relationships can suffer over time. Conflicts may arise.

The information in this section may help you keep your relationships safe from wear and tear. In this section, you will find strategies for dealing with your partner, your other children, your parents, and your friends.

### PARTNERS

#### How can partners help each other?

In times of stress, family members expect support from each other and some may believe a crisis may draw them closer together. However, it is possible that relationships may become strained.

Different people have different ways of coping and this can be a huge stress on the relationship. You might expect that your partner will feel and act the same way you do, but people deal with problems in very individual ways. There is no “right way” to feel during difficult times. Partners need to cope in their own ways.

Men and women usually express themselves in very different ways, which can strain the relationship. How each person copes with stress can also play a part. For example, some partners may try to cope with their pain by throwing themselves into their work; while others find it impossible to do even the smallest task.



*“Joe is incredibly technical and knowledgeable and I, on the other hand, miss the technical stuff and look at how Annie seems. I think Joe and I both feel that we make a really good team even though we come from totally different angles.”*

PARENT




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**RELATIONSHIP TIPS DURING A CRISIS**

Even though you may feel drained of energy, it is a good idea to spend time with your partner. Here are some tips for maintaining your relationship during a crisis.

Tips	Details
<b>Communicate</b>	<p>Communicate as openly and honestly as you can. You will have difficult decisions to make and may have conflicts to deal with. These are done best if you can be open and honest with each other. Make a point of setting time aside for talking and seeing how your partner is really doing. Do not expect your partner to be able to read your mind or your heart. Do loving things for each other. It will make you feel better.</p> <p>Make sure that both of you have read this part.</p>
<b>Privacy</b>	<p>Give your partner some privacy and distance when needed, but also come together and find ways that you can share your pain. Silence may cut you off from your partner's support. However, you or your partner may sometimes feel like silence is the only way to cope. Spend some time talking about your feelings and your child, but make sure you also spend time together doing and talking about other things. Find private time to spend with your partner. Some people make the mistake of giving all their time to their sick child. You and your partner need each other, and your child needs you both. Make time for yourselves without feeling guilty about it.</p>
<b>Give it time</b>	<p>Avoid making decisions about relationships during times of stress. It is often tempting to use a crisis as a test for the relationship, "If it doesn't work now, what good is it anyway?" but this is not a good time to think this way. Give your relationship some time.</p>
<b>Respect</b>	<p>Respect each other's ways of coping. Some people become completely consumed by a situation, while others do not allow themselves to feel the pain. A person who hides emotions may feel overwhelmed by his or her partner's emotional storm or see the partner as weak and unsupportive. A person who needs to deal openly with emotions may see a partner who is "getting on with life" as cold and unfeeling. Remember that there is no right or wrong way of coping with stress. Try to recognize and be accepting of your partner's way of coping even though it is different from your own. A crisis is not a good time to try to change your partner's personality or your relationship.</p>
<b>Don't take it personally</b>	<p>Try not to take your partner's anger or criticism personally. It is natural to take out your frustrations on a person you think will forgive you. Remember that the anger and negative feelings created by the situation may be directed at you but not meant for you. When you are upset by the anger and need to respond, it is usually less hurtful to express how you feel rather than accusing. For example, "I feel really hurt when..."</p>

RELATIONSHIP TIPS DURING CRISIS - CONTINUED

Tips	Details
<b>Sex</b>	Is the crisis causing conflict in your sexual relationship? Some partners may lose interest in sex because they feel tired and depressed all the time. Others may need more intimacy than usual as well as the release sex can offer. If you can talk about your sexual needs, there is less chance that one of you will feel rejected or resentful.
<b>Read</b>	Find out more about how a crisis can affect a relationship. There are excellent books and videos in hospital and public libraries, such as <i>The Impact of Chronic Illness on The Family: Marital Issues</i> .
<b>Support group</b>	Consider joining a support group where you can talk with other couples about their experiences.
<b>Counselling</b>	If you cannot reduce the stress in your relationship, consider getting counselling from a professional. Your social worker may be able to give you a list of counsellors.
<b>Share responsibility</b>	<p>Share responsibility for talking to health professionals and supporting your child. Often one parent becomes the “caregiver” of the sick child while the other works. This can create difficulties for both. The person who is working gets information second-hand and may feel left out or uninformed. The caregiver feels that the partner doesn’t understand what it is like at the hospital.</p> <p>If possible, try to schedule meetings with the health care team when you can both be there. If this is not possible, think about ways in which both of you can be part of discussions, for example, by arranging discussions on telephone extensions or by conference call.</p>
<b>Strengthen your relationship</b>	<p>Remember that during a health crisis, you, your partner, and your child are not likely to have the emotional energy to deal with the break-up of the family. Instead, try to use this time to support each other and strengthen your relationship.</p> 

*“At the moment I am home instead of at the hospital because Keith (sibling) decided this morning that he had had enough and needed me. Plan B required me to stay put and terrific Grandma is with Donna instead, and I will go in tonight.”*

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**FAMILY AND FRIENDS**

Sometimes the most difficult thing to do is admit that you need help and ask others to carry some of the load. Here are some tips for how to ask your family members and friends for help.

**Tell family and friends what you need**

Most people want to help, but not everyone knows how. They may not know what to say or what to offer. Their fear of saying or doing the wrong thing may cause them to avoid you. You may need to take the lead and show others how you want to be treated. For example, do you want to talk about your child openly and honestly, or would you prefer to use time with your friends to take your mind off your troubles?

It is hard for people to guess what you need, so you are more likely to get what you need if you give people some direct hints. For example, you might say, “I really don’t want to talk about this right now - I’d rather you help me take my mind off...” or “I can’t think about anything else. If we’re going to talk, I have to talk about...”

**Practice how to say it yourself**

At first it may not be easy for you to find the right words. It may be helpful to write yourself a “script”, either in your head or on paper. You can then practise it until you feel comfortable saying it aloud, and then use it whenever you need it to “break the ice”.

**Find other ways than saying it yourself**

Sometimes you may find it too hard to talk to people, even those closest to you. An answering machine lets you screen calls and handle them when you want to. Record a simple message such as, “Thank you for your concern. We’re often not able to come to the phone because we are caring for \_\_\_\_\_. Your call means a lot, so please leave a message, and we will call you as soon as we can.”

You can also call one or two people, and then ask them to call other family members and friends to keep them updated. This helps you avoid explaining a painful situation over and over again.

Most libraries have pamphlets, which help explain how friends can make life easier for you.

**SHARING EMOTIONS**

Sharing emotions, both the “highs” and the “lows”, helps most people cope with their child’s health problems. If your partner is not able to share and you do not have a close family member or friend, look for someone else with whom you can work through your emotions. Some possible support people are a social worker, chaplain, counsellor, hospital volunteer, or parent support group.

Parents, adult brothers or sisters, or a close relative such as an aunt, uncle, or cousin are the obvious people to call on for support. Before asking them for support, consider whether they will be able to give you the support you need without adding stress. For example, some people have different beliefs and values, and others like to be in charge of situations. This may lead to many disagreements. During a health crisis, you and your children’s needs are the priority.

**Grandparents**

Grandparents can be wonderful support people but they may also find the situation especially hard. Not only are they concerned for their grandchild, they may also feel helpless about their own child's problem. You may find yourself comforting rather than being comforted. Limit how much you share until you are sure how much support they will be able to provide.

**Your older children**

Avoid asking older children for emotional support. It may be very tempting to look to your older children for emotional support, particularly if they are healthy teens. In most cases, this should be avoided for several reasons. Your emotional stress can be a great burden for a teen to carry, particularly as the teenage years are already very stressful for most children. In addition, if your teen does not want to share, it may cause a rift in your relationship. However, it is important to keep communicating with your teenager so that your teen feels you are being open and honest and at the same time feels that he or she can talk to you about feelings and concerns.

**Roles for people**

Some people want to provide comfort, but they end up irritating you or draining your energy. You don't need to completely leave them out if you want to avoid hurting their feelings. You might give them a role to play outside of the hospital. For example, ask them for help with shopping, laundry, driving, or making phone calls.

**SURVIVAL STRATEGIES FOR SINGLE OR DIVORCED PARENTS**

CHDs affect all kinds of families, including single parent and divorced or separated families. Parents in these situations have added stress and responsibility. Here are some tips for single, separated, or divorced parents that can help in stressful situations.

**Making decisions with a buddy**

Many single parents make all of their day-to-day decisions on their own. However, most people need someone to help them sort through the information to make important decisions. At times, you may have to call on all your inner strength to manage a health crisis. It is helpful if you have a supportive circle of family and friends. From your circle of family and friends choose a "buddy" that you trust. Find out whether your buddy is willing to help you make decisions about your child's care. Make sure he or she has the background information you already have before you discuss plans and decisions. Offer your buddy useful books or articles. Take notes (or ask a staff person to do this for you) when you have meetings or conversations that will affect decisions.

A buddy who knows you and shares your beliefs and values can become a true support when you have difficult choices to make. Keep your buddy up-to-date on the care plan, even when things are going smoothly.

**Making decisions with a former partner**

Unless one parent has sole custody of a child, both parents will likely be involved in making decisions. In the interests of the child, parents who are separated or divorced need to work out a way to share information.



*"I know we will make it through all the hurdles that come our way, thanks to all of your prayers, good thoughts, and good wishes. I look forward to one day sharing with Susie all the inspirational e-mails that we have received on both of her hospital stays."*

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*“I felt very alone when my daughter was born. My family members weren’t very supportive at first, but I worked on them and they came around. A few of the veteran moms took me under their wing and I talked to them for hours - that helped.”*

PARENT

*“When some of the members of my support circle asked how they could help, one friend suggested that they ‘buy lunches for a week’ or ‘fill her cupboard along with yours next time you grocery shop’. It certainly helped make ends meet.”*

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Communication with the health care team can take up a lot of time. It is not possible for the health care team to meet separately with each parent.

You can share information by making sure that you both go to scheduled meetings. If this is not possible, agree as to who will attend meetings and take telephone calls from the doctor. This parent will then make sure the other one gets the information.

Sharing information and making decisions with a former partner may be especially hard if your relationship with your former partner is strained. A health care professional such as a nurse, social worker, or other professional support person may be able to help you set up a communication plan that works for both of you. A social worker often has many practical ideas, based on what has worked for other couples in similar situations.

### Dealing with your emotions alone

Parents who do not have a partner to share with may find it particularly difficult to cope. For more information about finding a support person see *Sharing emotions*, page 6-4.

### Dealing with fatigue

As a single parent of a child with a CHD, it is hard to avoid becoming over-tired. Your responsibilities may seem endless and the burden overwhelming. Your child’s health care needs will likely be long-term, and right from the beginning you need to conserve your energy. How you start sets a pattern that your child will come to expect. If you never leave your child’s side, he or she will expect you to always be there, even when the current situation has passed.

If there are people in your support circle with whom your child is comfortable, ask them if they are willing to visit your child from time to

time. Work out a plan that will fit into the person’s schedule. For example, one person may be willing to spend the night, while another may be willing to give you a break during the dinner hour. Your child will quickly come to see this person as part of the care team, allowing you time to catch up on sleep and necessary chores.

You may find it hard to ask for this help from your family and friends. However, most people welcome the chance to show their care and support.

Take breaks when staff members are with your child, for example, during hospital routines, play room activities, and school times.

Talk to the social worker about other available resources. For example, a volunteer may be able to come at certain times to play with your child. There may also be services outside the hospital, such as respite services, which offer in-home childcare for varying lengths of time.

While it may seem like a lot of work to take the initiative and contact agencies and other parents, it is well worth the effort.



**MONEY MATTERS**

Very few people manage to get through a child's health crisis without changing their work time. This often means a loss of income, so careful planning is important. If you need financial assistance, talk to the social worker about available programs and resources. If your child's other parent is able to provide some help, involve him or her in the plans.

**You may want to consider whether:**

- there are benefits in your work contract that will allow you to care for your sick child,
- a leave of any kind is possible,
- there are resources for you, such as social or religious societies.

Before you go to an organization for financial help, take the time to figure out where you need help.

**Being the parent who is not the regular caregiver**

If you are a parent who does not have day-to-day responsibility of caring for your child, you have your own challenges to face.

**The following tips may help everyone involved, including you, your child, and your former partner:**

- agree as to how you will be involved,
- plan how you will stay informed about treatment plans and your child's progress (see *Making decisions with a former partner*, page 6-6),
- if you had little involvement in your child's life before the crisis, your child may not want to see more of you now,
- if your former partner welcomes support, consider what kind of support is needed and how you can provide it,

- try to avoid bringing any personal conflicts between you and your former partner into the health care situation. Remember that no one needs extra stress during a crisis. The social worker may be able to offer help or names of resource people if conflicts arise.

**SIBLINGS**

**How can we make sure our other children get the care and support they need?**

You have barely enough time and emotional energy to care for your child with a CHD—you may wonder how will you give your other children the support they need? Many parents later feel guilt and regret, believing that their relationships with their other children suffered during times of increased stress and anxiety. It might help to know that most siblings recover, and some may even benefit. For example, some children become more independent and mature, and some learn to empathize (understand what others are feeling) more.

There are steps you can take to ease the way for your other children. Here are a few suggestions from health professionals, parents, and siblings.

**Tell siblings what is happening in a way they can understand**

You may be worried that you will frighten your other children by sharing too much information. However, even very young children are likely to sense family anxiety, and it can be disturbing when they don't understand the problem. They may imagine things that are more frightening than the reality, or they may blame themselves for upsetting the family. A simple version of the truth that is suitable to their age is best.

*"When I was little, I worried that maybe I would catch it (be sick like her brother) or something, or that, because my brother came from my mom that she would get it. I worried that someday I would have to go to the hospital because I had caught it."*

**SIBLING**

*"I focused on the other kids - on what they were doing. We found a new normal together."*

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*"I know I can't  
fix my brother's heart  
or stop my mom from  
worrying. I'm just  
thirteen years old.  
But I can make my  
mom a cup of tea and  
tell her I love her."*

BROTHER

*"Keith decided last  
week, after not seeing  
me for 7 days, that he  
was not a happy little  
fellow, and so I had to  
swallow my fears and  
rely on the nurse, my  
mother and siblings to  
be with Donna when  
we weren't there"*

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**Try to:**

- Ask them questions. Find out what they'd like to know and what worries them.
- Create an open atmosphere so that your children know they can ask you about anything and express all their feelings, including anger and jealousy.
- Use words and examples that they can understand.
- Remember that you may have to repeat information several times.
- As your children get older, give them more detailed information.

**Here are some examples of what to say to your healthy children:**

- A congenital heart defect is a serious problem. It will not just go away like a cold. It needs a lot of treatment. It may take a long time before \_\_\_\_\_ (your brother or sister) gets better.
- Most children with heart defects can be helped. The doctors, nurses, and we, as a family, will work hard to make \_\_\_\_\_ well again.
- Nothing any of us did, thought, or said, caused \_\_\_\_\_'s CHD. No one knows why or how people get CHDs, but we do know CHDs are not contagious - you can't "catch" one from being with \_\_\_\_\_.
- When someone we love is very sick, it makes us all feel bad. People feel bad in lots of ways. Some people feel sad, some feel angry, and some feel afraid. You can't help how you feel, but sometimes it helps to talk about the feelings.

- \_\_\_\_\_ needs us more than usual while he is sick. That is why things at home are different than usual. We need to be kind to each other and remember that we all love each other just the same, even though sometimes it seems things aren't fair.
- It is all right for you to enjoy things and have fun even though \_\_\_\_\_ is sick. If you'd like to help, you could... (make a card for \_\_\_\_\_ wall, make a tape of favourite songs) or help the family at home by... (folding the laundry, setting the table).

**Be aware of your other children's feelings**

Your other children are likely feeling anxious and fearful because their lives have suddenly been thrown off balance. Parents who are usually available to make them feel secure are now away a lot, and when the parents are home, they are often distracted and upset.

It is less difficult for your other children if you let them know how you are feeling without asking them to help you make decisions. It is also helpful to let them know that you are able to cope with the situation most of the time even though you seem upset. For example, if your teenager finds you crying or you blow up at him, it can be harmful to say something like: "I feel so scared and lonely, I don't know what to do. I don't know what I would do without you." Instead, you might say something like: "This is really scary for all of us. I'm feeling pretty down today. I have some bad days, but I know we can all get through this together. How are you feeling?"

Remember that children *need to get support rather than give it*. Your children cannot provide the kind of support you will need to get through a stressful situation. However, children often need to be helpful, so give them



opportunities to be part of the family team, for example, by saying, "I'm feeling sad today. It would help me if you played a game with your little brother while I make dinner." Be careful about asking your children to put the sick child's needs ahead of their own on a day-to-day basis, or they may become frustrated and angry about the burden it puts on them.

**Give your children the opportunity to express their emotions, even negative ones**

Like you, your other children have been thrown into emotional turmoil and will probably have many conflicting emotions: concern for you and for their sibling; jealousy over the attention their sibling is getting; fear and uncertainty, abandonment, sadness, anger, and guilt. It is normal for the healthy children to have negative feelings and to change the way they behave.

Jealousy, anger and resentment are normal feelings in siblings (even in siblings of healthy children). Your child is not 'pathological' or abnormal because he screamed at the baby or hit his brother. Expect some negative behaviour, and do your best to give them the chance to voice 'bad' feelings (anger, jealousy) without scolding them. Let them know that it's all right to feel that way sometimes but that hitting others is not okay. Your child may need help expressing sad feelings as well; many siblings feel they need to be 'strong' for their family. Be honest about your own emotions and let them know you can be sad together.

Young children will have a hard time expressing their feelings in words. You may need to help them find other ways. For example, you might ask your child to draw a picture (of her

family or her sibling) and then ask her to tell you about the picture. Watch for 'clues' to her emotions and ask questions.

One way to help your other children is to offer them books or videos for children that are available in the parent library.

**Tell your children that this is not their fault**

Young children sometimes have unreal ideas about why things happen or what caused a problem. This magical thinking can happen with children and adults. Some children may blame themselves for what is happening. For example, your son may feel that, because he didn't want a sister, he caused her heart defect. From time to time, tell your children that what happened was not their fault.

**Have special "alone time" with your other children**

Many siblings say they resent all of the attention that goes to the one who is sick. They feel better when their parents set aside time that is just for them. Some parents report that setting aside this time can be difficult, particularly if one child is hospitalized. For those times, they suggest finding another adult who can make the child at home feel special and offer support by listening and talking. This can be a good way to involve grandparents or close friends who want to help.



*"Maggie is smelly - she smells like a hospital and I hate that smell."*

**SIBLING**

*"Our oldest, who was 4, had some behaviour problems... he was fine with his baby sister, but was physically aggressive with his 2-year-old sister.*

*Our cardiologist referred us to the staff child psychologist... it was comforting to find out that our son's behaviour was normal given the circumstances."*

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*“Whenever the boys come to see Debbie it’s wonderful how she perks up and watches them with such great interest. The bond among siblings is amazing.”*

PARENT

**Include siblings in the experience if they wish**

A serious illness affects everyone in the family, and everyone needs the chance to be involved and feel useful. Siblings will find long hospital visits tiring, but might like shorter visits. Plan visits carefully, and talk to them about what they will see.

If your other children don’t want to visit the hospital, consider taking photos of their sibling so they can feel like they are “in touch” with their sibling, and so they can get an idea of where you go and what the hospital ward looks like. They can also be made to feel like they are the ‘expert’ in certain areas, such as choosing toys to bring to the hospital, drawing pictures for their sibling or the nurses, or making tapes to be played in the hospital.

**Try to be fair**

Children with CHDs often get gifts and treats from friends and relatives. Having a few things on hand for siblings at those times will help to reduce jealousy and resentment. If someone asks what they can give your child, suggest something that siblings can also enjoy, such as a video, game, or book.

Siblings often report that they have to do more than their share of the chores at home. To keep things fair, try to find simple chores that the child with a CHD can do.

**Provide opportunities for siblings to meet other children in the same situation**

Many parents seek out other parents to talk to and share with, but don’t think to provide the same thing for their children. Talking to other siblings who understand and share their experience may be very helpful. Just knowing that there are others out there, and that they are not alone, can be reassuring.

**Let teachers know that siblings might be experiencing stress**

Your children’s concerns may affect their work at school. Ask their teachers to watch for problems and provide extra support if needed.



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## Grief and bereavement

Although most children survive their heart defects, some do not. Some parents want to “prepare for the worst”. You can never really prepare for this but you can make the most of your time with your child.

**W**hen you hear that your child has a heart defect, it may cause an overwhelming feeling of grief. Thinking of your child’s death can cast a long shadow over your lives. No matter how hopeful you are about your child’s future, it is natural from time to time to feel the chill of that shadow.

Sharing your feelings with someone close to you may help you make the situation easier to talk about.

### How can we prepare for the death of our child?

Nothing is as painful as losing a child. The pain is often made worse because our society is not very good at dealing with death, especially the death of a child. That’s why so many of us need help to deal with this situation. Help may come from a family member or friend, or another parent. Accept it wherever you find it.

Some parents are still hopeful even at the hour of their child’s death. Others say that they can remember a time when their hope shifted from recovery to a hope for a peaceful death.

Children deal with death differently too. If reading helps you, there are some books in the *Additional Supports and Resources* section, page 12-1.

### If you know your child is dying

Sometimes there are warning signs, which give you some time to prepare. You can use this time to lay some of the groundwork that will help you and your family through the difficult days, weeks, and months to follow.

It helps to have control over some parts of your child’s last days. The health care team can help you find ways to take some control, such as choosing who will be with your child, and whether your child will die in hospital or at home.

### Am I going to die?

There may come a time when your child asks this question. Some ask when they are feeling very ill; some never ask. Let your child decide whether to talk about dying or not, but make sure your child knows that you are willing to talk about difficult things.

How you answer this question will depend on your child’s situation. Unless your doctor has told you that there is little more that can be done, we suggest you reply, “You are being treated so you can get better. We all die eventually, but you are not going to die now.”

For an older child with a serious heart problem, you may want to offer the chance to write a “living will”. A living will gives this older children a chance to make decisions about their final days.

### Preparing the other children

If you have other children, you will probably want to tell them that their sibling is dying. Explain what is happening using simple, clear words. It is best to be direct, even if it is painful and difficult. It would be confusing to say, “Your brother is going to pass on”.



### YOU MAKE IT PART OF YOU

“LIVING AFTER THE DEATH OF A CHILD IS NOT DONE ACCORDING TO A FIXED PATTERN OF EMOTIONS.

THE VARIOUS FEELINGS AND EXPERIENCES ARE MORE LIKE CHANGES IN THE WEATHER.

ABOUT THE TIME YOU BELIEVE THE STORM HAS PASSED, YOU FIND IT RETURNING TO STIR YOU AGAIN.

SOME PARENTS HAVE DESCRIBED THEIR GRIEF AS COMING IN WAVES.”

JOY JOHNSON AND DR. S.M. JOHNSON, CHILDREN DIE, TOO (1992)



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**DEALING WITH DEATH**

“TALKING ABOUT DEATH - EVEN THINKING ABOUT DEATH - HAD ALWAYS BEEN DIFFICULT FOR ME.



ERIN'S ILLNESS BROUGHT ME FACE-TO-FACE WITH THE MOST DIFFICULT DEATH POSSIBLE...THAT OF MY OWN CHILD.



THE MORE I BROUGHT MY THOUGHTS AND FEELINGS TO THE CONSCIOUS LEVEL, THE EASIER THE SUBJECT OF DEATH WAS TO THINK AND TALK ABOUT.”

THE LAST DAY OF APRIL, BY NANCY ROACH



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You should also make sure your children know that the death of their sister or brother was in no way caused by them or by their thoughts or feelings. Some children think that because they had mean thoughts about their sibling they somehow caused the death. This “magical thinking” is very common in children. Give them chances to talk about their feelings, and don’t judge them, even if their thoughts and feelings seem very negative.

**What can we expect from the health care team?**

**When treatment is no longer working, you can expect the health care team to provide:**

- honesty,
- a plan for helping your child to live life to the fullest with as little suffering as possible,
- support for decisions,
- respect for your choices, and help to make them possible,
- help for your family as they come to accept that the child is dying,
- help with pain and other symptoms,
- support for your choice of where to care for your child,
- treatment and care information for community health care providers (if needed) as they help you care for you child,
- contact after your child’s death.

**Making memories**

Any time together is meaningful, and you need to spend this time in the way that is right for you, whether you are at home or at the hospital.

Some families choose to create tokens of their child and their time together. You might want to take pictures or make audiotapes or

videos of your child with the family. You may want to make a plaster hand or foot mold, or keep a lock of your child’s hair. Do whatever feels right for you, and don’t worry about what other people might think.

**Saying goodbye**

Take the time you need to say goodbye. (North Americans are often not very comfortable with death, and sometimes try to remove all signs of it as soon as possible.) If you need some time to hold, dress, or bathe your child, take it. Don’t let hospital staff, family, or friends make you feel rushed.

**The grieving process**

There is no pattern to grief, but there are some common feelings, such as anger, sorrow, and deep loneliness. You may also have emotions that you do not expect: relief because the worst is over, ambivalence towards your other children (often because you are exhausted), and guilt that whatever you did for your child was not enough. At first, you may feel nothing at all. Many parents feel numbness due to shock, which is the mind’s way of protecting you from too much pain. Some feel the most intense pain just when they expect to start feeling better.

You may have some of the common physical symptoms of grief. They include forgetfulness, lack of concentration, trouble hearing (a need to have things repeated), exhaustion, insomnia, nervousness, headaches, stomach problems, loss or gain in appetite, restlessness, dizziness, and disorientation. These physical things are normal to a point, but if they go on too long, talk to your doctor.

Let yourself express grief in your way—don't worry about what other people think. You may want to write. Some parents deal with the anger they feel by writing letters that they will never send. Some keep a journal. Talking to a trusted friend or counsellor can also be very helpful: telling and retelling your own story is a common way of understanding what has happened and coping with what has happened in your life. You might consider joining a support group where you can work through some of your thoughts and feelings with others who have been in a similar situation. You can't heal well unless you grieve well and deal with the storm of emotions that you feel.

You may find that your religious faith plays a key role in guiding you through your grief. On the other hand, you may question your faith and feel a lot of anger. It is very common to feel confused about your faith and beliefs with the loss of a child. Either way, talking with your religious leaders or spiritual guides may help.

Grief is exhausting, and may consume your life for quite a while, sometimes long past the time when other people think you should be "getting on with your life". Take the time you need.

At the same time, you need to be aware of possible problems. Pay attention to any warning signs that your grief is affecting your mental or physical health.

**You may need some help if you:**

- think about killing yourself or do things that are dangerous to yourself,
- cannot do daily activities several weeks after your child has died; be concerned if you cannot do anything at all,
- become accident-prone,
- act strangely (for example, if you become destructive, or do something you wouldn't ordinarily such as shoplifting),

- have constant feelings of rage and hostility,
- consistently use alcohol or drugs (even over-the-counter medications) to ease the pain of grief,
- have difficulty eating or sleeping several weeks after your child has died,
- refuse to be comforted by anyone,
- remove yourself from family and friends.

These are only warning signs and do not mean there is a major problem. If you think about how strong the feelings are and how long they last, you may be able to decide if you need professional help. You may also want to talk to the clinic's social worker or your family doctor, who can refer you to a psychologist, family counsellor, or other grief counsellor.

**Couples**

The loss of a child is very hard on a couple. You may not be able to be the "strong one" for your partner because you are just as upset. While you need to find ways of grieving together, you shouldn't expect your partner to be your only support.

For suggestions on how to deal with grief, see *How can partners help each other?*, page 6-1.

**Siblings**

The death of a family member is hard to accept and understand at any age, but for young children it is very confusing. Try to explain death in words that they can understand—avoid saying "passed away" or "lost". Don't feel that you must have all the answers—saying "I don't know" is okay. Children under five don't understand time and death, and may keep asking when their sibling is coming back. This can upset you, but try to be patient and continue to talk about their sibling; this helps them develop their ideas and feelings about death and their sibling.

*"I decided that when her quality of life was gone then it was time to stop doing all of this... She had no fight left, so we stopped all the treatment. That night she laughed, she even crawled and was happier than she had been in the last seven months: no IVs, no medications, no doctors, no ventilator. She was so happy!"*

PARENT

*"I would get so angry at him because he didn't seem to be feeling my pain. He seemed to be able to go to work and carry on and I couldn't even get out of bed."*

PARENT



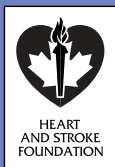
**Finding answers. For life.**

*“I thought about dying, about killing myself, nothing seemed worth staying for. But after a while, life seemed worth it again - I had some happiness with the sad.”*

PARENT

*“I got really mad when a friend phoned and left a message suggesting that I seek help or find someone to talk to. She was trying to help, but I couldn't accept it. I wanted to feel this way, I had to feel this way, and to seek help for it seemed to me like asking me not to feel this pain for my son.”*

PARENT



Finding answers. For life.

Your children will have their own ways of coping and understanding what has happened. Try to allow them to deal with their own feelings of loss, not yours. Children's grief often runs in cycles—they may be terribly sad at one moment, and then seem very carefree the next. This cycle is normal and healthy, and most children find a balance between grief and normal daily routine and happiness. Let them feel happy or sad, mad or glad without guilt. Each of you in the family has the right to feel the way you feel and be accepted and supported by others in the family.

Children will sometimes fear that they or their parents might be the next to die. You may find that your children cling to you more and act younger than normal. Offer lots of hugs and reassurance. Children may also play at being sick or dying. While this may be disturbing, remember that children use play to understand and master their world.

If you feel that your child is having problems coping, there is support available. Talk to the clinic's social worker, nurse, or your family doctor who can put you in touch with professionals or peer support groups.

Helping your children through their grief can seem overwhelming when you can hardly keep yourself together. If you are distraught and can't care for your children, ask someone they like to spend time with them. If you get angry with your kids or cry, try to reassure them. Explain that you are angry or sad because of your grief and not because of anything they did or said. Apologise when your behaviour is upsetting, and give them a chance to forgive you. This can be an appropriate time to share your grief and talk about what has happened.

### Understanding the reaction of others

Most people will never suffer the death of a child, but are afraid that they may some day face what you are experiencing. Many family members and friends will not fully understand what you are going through and may have a hard time supporting you. They may say the wrong things or offer the wrong kind of help. Tell them, when possible, what you need and how you are doing. It may be very helpful to get support from other parents who have had similar experiences, or from people with training in grief support.

Relationships with family members can become strained with the loss of a child. Remember that grandparents, aunts, and uncles will themselves be grieving and may not be able to offer much support. Try as much as possible to tell them what you need, but be patient if they are unable to give it.

### Learning to live beyond the shadow

Eventually the good days start to outnumber the bad, and you begin to find yourself again. No one can tell you when this will (or should) happen. You may find that you are still deeply grieving while your partner has begun to heal. Be gentle with each other and try to accept the fact that you will probably follow different paths.

There will always be “what ifs” and “what might have been”, but the sadness shouldn't overshadow the happiness you had with your child. Happier memories will eventually outweigh the pain. You may want to create a reminder of those memories, plant a tree, write a tribute, have a portrait drawn, or make a quilt. Be creative, and include your family as much as possible.

*Celebrate your success as you begin to heal and plan again for your future.*

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■ Dozois E., Kneeshaw R. *Heart Beats: A handbook for families and children with special hearts.* Edited by Work on the Street Consulting. Heart Beats - the Children's Society of Calgary, 1999 (draft).

■ Durbach E., Stutzer C. *Children with cancer: A handbook for families.* British Columbia's Children's Hospital, Vancouver, 2002.



*"I felt so sad that my chest hurt - I thought maybe I was getting a heart problem because my heart hurt so bad."*

PARENT

*"I realized later that my family just didn't know what to do for me (although I thought they should be able to read my mind and my heart). I was often mad at them through that first six months, but as time passed we talked and shared in small ways, and those small moments healed some of those big hurts."*

PARENT

*"After Mac died, a friend gave me a beautiful wrought iron garden bench that will last forever. I love to sit out in the garden and remember. In the winter, I leave it out so I can think of the coming spring..."*

PARENT

