



BC Cancer Agency
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Reaching Out to Your Children When Cancer Comes to Your Family: A Guide for Parents



by June Slakov

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Reaching Out to Your Children When Cancer Comes to Your Family: A Guide for Parents

Written by: **June Slakov**, BA, DVATI, RCAT, Art Therapist

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BC Cancer Agency

Vancouver Cancer Centre

600 W. 10th Avenue

Vancouver, BC

Canada V5Z 4E6

Phone: 604.877.6000 x 2194

or toll-free at 1.800.663.3333 x 2194

Fax: 604.872.4596

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Foreward

June Slakov has written an informative guide to help you and your family talk about the impact that cancer may have on your lives. *Reaching Out to Your Children When Cancer Comes to Your Family: A Guide for Parents* is a companion book to the *Time for Me* Activity Book developed by June and other health care professionals for children.

June is an Art Therapist and has been facilitating programs to support children when a family member has cancer for the past 14 years. The suggestions in *Reaching Out to Your Children When Cancer Comes to Your Family: A Guide for Parents* reflects her work with other health care professionals and families, and advice from other experts in research and the literature.

Although the guide focuses on the parent who has cancer, it would be useful when any family member has cancer. It will give you ideas about what to expect from your children, what you can do and might say and where you can find more information. There are suggestions about what you may want to discuss as a family and as well with your children individually, depending on their ages and maturity.

Before you talk to your children, consider what you know about your illness and treatment and how you want to share this with your family. Having a plan helps to reduce anxiety in times of uncertainty and helps you to focus on living with cancer. If you are experiencing emotional difficulties, consider seeking support – talking to your spouse or partner, or asking to meet with a counselor.

The creation of *Reaching Out to Your Children When Cancer Comes to Your Family: A Guide for Parents* was made possible through the generous support of the Order of the Eastern Star – Grand Chapter of BC and Yukon. We welcome your comments and suggestions about this booklet.

Gina MacKenzie, MSW,
Regional Professional Practice Leader, Patient & Family Counselling Services,
BC Cancer Agency – Vancouver and Fraser Valley Centres

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This guide for parents was prepared by June Slakov using information gathered from the sources listed within the body of the text and at its end (Selected Resources for Parents). *Reaching Out to Your Children When Cancer Comes to Your Family: A Guide for Parents* was created out of our work with children and families in Patient & Family Counselling Services at BC Cancer Agency, whose courage, wisdom and challenges continue to inspire us. “Blessings on you,” my wise colleague, Karen Janes, would say to all of these families.

We would also like to thank our counselling teams of health professionals in Patient & Family Counselling Services and Nursing at BC Cancer Agency whose valuable contributions over the years have helped to shape this work:

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We give our special thanks to the children and families who have lent us their wonderful tile images and stories that you see here, from Revlon’s Arts in Medicine Tile Tales Project at Vancouver Centre and Fraser Valley Centre. They go to the heart of the matter for us all.

A word about this book

This book is for the parents – grandparents, aunts and uncles, teachers, or other support persons, who play a key role in helping children and teens who have a family member living with cancer. It has been said before, and we need to say it again. Cancer affects all members of the family. We believe that helping children can help to strengthen the family’s ability to cope.

We hope that this guide will help to open the way for parents and their children to talk with each other, to understand each other, to learn from each other, and to help each other. We have designed the guide in order to point the reader towards other sources of information that may be needed along the way, sources that we have found to be both useful and sound.

Karen Janes, co-author of the children’s activity book *Time for Me* and dedicated co-facilitator in the Children’s Support Group Program at Vancouver Centre, has a real presence in this guide. It seems fitting then that each of the chapters begins with a quote from her article *Talking with Your Children About Cancer*.^{*} The phrase “begin with love and trust” best describes the foundation of our work with families, and is an inspiration for parents to nourish the seeds of growth and change in their children when a family member is living with cancer.

* Karen Janes (2005). Talking with your children about cancer. *ABREAST in the WEST*, 6(2), 7.

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One day at

Chapter 1

Finding Out About the Diagnosis



“One Day At a Time” by Anju Dhaliwal

One day at a time.

“Begin with love and trust. It is very difficult to keep cancer a “secret”, particularly in a family. Even very young children can sense that something is wrong, and they may have questions, worries, and fears. In the absence of accurate information, children might use their imaginations or misconceptions they may have heard to understand what is happening. Include them in explanations early in the family’s experience with cancer.”

— (Janes, 2005, p.7)

Overview of Chapter 1

- Why tell your children?
- When do you tell?
- Who should tell?
- What do you talk about?
- “What if...?” questions
- Will your children be ok?

Chapter 1 – Finding Out About the Diagnosis

Talking with your children about your diagnosis

Why tell your children?

Why are children less anxious, and function better in the long run when they are told the truth?

- Your children will realize they can trust and count on you.
- It is not usually possible to hide a serious diagnosis.
- Secrets use up valuable energy.
- Your children can sense that something is wrong even when nothing is said.
- Your children are often more aware than you realize, and your teens are very observant.
- It is inevitable that your children will overhear something.
- When your children don't understand what is happening, they will likely become anxious.
- Without the truth, your children are likely to imagine something far worse.

It is natural to want to protect your children from distress.

Why would not telling the truth make things worse?

- Your children may feel excluded.
- While you may want to avoid your children's sadness, anger, or questions about death, there is a serious risk of losing your child's trust.
- Not telling the truth can lead to additional family stress for you to cope with.

When do you tell your children?

- As soon as you are able to do this, talk with your children.
- Give yourself time to absorb the news of your diagnosis.
You may experience some of the following: shock, worry and fear for the future, guilt over lifestyle or diet or letting the family down, anger at this happening, sadness or grief.
- When you feel ready, talk with your partner or other adult support person about what you would like to say to your children.

Avoid surprises!

See

Hamilton, J. (2001).
*When a Parent is Sick:
Helping Parents Explain
Serious Illness to Children.*
Lawrencetown Beach,
Canada: Pottersfield Press.

What should you talk about?
10-12.

1. **Things to consider as you talk to your children, 17-27.**
2. **Examples of what to say, 25-41.**

Who should tell your children?

- Both of the parents should decide how and what to tell your children.
- If both of the parents are unable to agree on what to tell your children, it may be helpful to talk this over with a counsellor.
- You may want to write down what you wish to say.
- If either or both parents feel unable to talk to your children, select someone who can, and be present in that conversation.
- If the parent with cancer is not able to be present, have the other parent or close family member take the lead.
- A family meeting is usually the best way to share the news.

What do you talk about?

- Children don't need all the information, but they need to hear the truth.
- Children need to understand what's going on in language they can understand.
- Children need to have the opportunity to ask questions.

Children do better when

- they are included in explanations early
- information is not overheard
- they are kept up to date
- they are reassured that:
 1. you will continue to talk with them about what to expect over the next while
 2. they will be looked after no matter what
 3. you want them to continue their activities and will help them do this
 4. they are involved – talk with them about how they can help

Making a plan

- Try not to see this as one big conversation, but the first of many.
- Information can be given in steps.
- You should not give up after one try.
- With younger children, be prepared to explain many times, and to answer the same questions.
- Welcome children's questions, and let them know it is ok to talk with other adults (parent's doctor, nurse, grandparent etc.).

A good plan for discussion would include:

1. **Information about the cancer**
2. **feelings and concerns**
3. **changes which may affect your children**

1. Information about the cancer

Using simple language, give a brief statement of what has occurred.

Tell your children

- the name of the illness
- what part of the body is affected
- how it was discovered
- what will be done to treat your illness

Calling your illness a "boo-boo" may confuse children about common illnesses being as serious as cancer.

Tell your children basic facts about cancer.

1. Cancer is no one's fault.
Your children have not caused your cancer.
Nothing that they have said, done, or thought can cause your cancer.
2. Cancer is not like a cold or flu.
Your child cannot 'catch' your cancer.
3. It is not always clear why cancer develops.

Ask your children

- What do they know about cancer?
- What do they want to know?
- What did they hear you tell them (or how would they explain it to a friend)?

2. Feelings and concerns

You can encourage your children not to worry alone.

1. Reassure your child that it is normal to feel frightened, sad, or angry.
2. Let your child know right at the start that it is normal for children to wonder if their parent is going to die.
3. Let them know that it is ok to talk about death.

3. Changes which may affect your children

Reassure your children that:

- everyone in the family needs to adjust to the news
- you will get through this together as a family
- they will be looked after
- you will continue to talk with them
- you will let them know what will change and what will be the same
- you want them to continue their activities and will help them do this
- it is important for them to play and see their friends

Encourage their questions.

Accept their unwillingness to talk.

See

Hamilton, J. (2001).
*When a Parent is Sick:
Helping Parents Explain
Serious Illness to Children.*
Lawrencetown Beach,
Canada: Pottersfield Press.

Addressing the future, 12-13.

“What If...?” Questions

What if your child asks if you are going to die? (most feared question)

- All children, except very young ones, wonder if cancer means you are going to die...even if they don't ask the question out loud.
- It is a good idea to address the topic from the beginning, so that you and your children do not have to be on your guard.
- You could say, for example, that some people do die from cancer, but that many people are cured, and many others live for a long time with their illness.
- While acknowledging the real uncertainty around the disease, you can lead the way in hoping for the best.
- You could say something like, “I will do everything possible to take care of myself and have the best possible treatment, so that I can live for as long as and as well as I can.”

What if you cry?

- Know that it is healthy.
- Your children will see that it is ok to feel and show feelings.
- Offer reassurance
 - Young children: Tell your child that it is *not your child's fault, you are sad because...*
 - Preteens: They may be a bit scared. Tell them that *you and your health team are working hard.*
 - Teens: Tell teens that it is normal to have unpleasant feelings and you will get extra support to help with feelings and concerns.

What if you can't answer your child's question?

- It is normal for parents to have lots of questions themselves.
- It is normal not to have all the answers.
- Let your child know you will try to find out and get back to them.

Will your children be ok?

- It is not possible to protect children from worry.
- Give your children time to adjust.
- Respect your child's usual way of coping.
- Continue to have as much 'normal' routine as possible.
- Provide opportunities to talk together.

Chapter 2 Children's Reactions



"Field of Wind" by Ryan Chislett

“Many children will ask if cancer is contagious, or about what caused your cancer, or whether anyone else in the family will get cancer. You may wish to reassure them that cancer is not contagious and that they are strong and healthy. Children often feel guilty and responsible, as if their behaviour or feelings have resulted in the illness. It is very important to reinforce that nothing they have done has caused the development of your illness.”

— (Janes, 2005, p.7)

Overview of Chapter 2

- Children’s normal reactions to the news of a parent’s cancer
- Guidelines for supporting children at different developmental stages
- Children’s reactions – what they say

Chapter 2 – Children’s Reactions

How do children normally react to the news of their parent’s cancer?

- Children react differently at different ages.
- All children worry about ‘who will look after me?’
- Older children may also worry about what will happen to their parent and what is going to happen over the next few months.
- It can be more stressful for teens.

What reactions can you expect?

- young children:
 - have short attention spans, may become easily impatient or overwhelmed
- pre-teens:
 - can focus longer, may avoid, be silent, seem unconcerned – may not understand, may have uncomfortable feelings
- teens:
 - may find it embarrassing, may cry, may ask questions, or keep everything inside
 - may change the subject to a normal topic like ‘When’s dinner?’



Video Series
We Can Cope: When A Parent Has Cancer (2000).
Inflexion: Newton, MA.

Parent Tape, Teen Tape,
Child Tape

and

Hamilton, J. (2001).
When a Parent is Sick: Helping Parents Explain Serious Illness to Children.
Lawrencetown Beach,
Canada: Pottersfield Press.

3. A child’s understanding and response to a parent’s serious illness, 42-59.

Guidelines for supporting your children at different developmental stages

Infants and Toddlers

Reactions

- Very young children can't understand illness, but they can sense change.
- Infants and toddlers may react with irritability, or disturbances to eating, sleeping, or eliminating patterns.
- Separation from the parent is the main source of distress.

How you can help

- Try to maintain as much routine as possible (where they sleep, what they eat, what they play with).
- Have a few consistent caregivers.
- Provide opportunities for warm care giving (holding, soothing, talking to and playing with).

Pre-schoolers (3 – 5 years old)

Reactions

- Pre-schoolers are better able to understand illness.
- Magical thinking can lead them to fantasies that they have caused the illness.
- They have concrete expectations and short time frames. They may believe that bandages, creams, and pills will cure the illness quickly.
- They cannot tolerate strong emotions for long.

How you can help

- Keep in mind suggestions for helping infants and toddlers.
- Understand that pre-schoolers believe that death is temporary and reversible.
- Be prepared for direct and many questions about death and illness.
- Reassure your child that
 - illness is not a punishment
 - child did not cause illness
 - child cannot catch cancer
- Keep your answers brief.

School-aged children (6 – 12 years)

Reactions

- School-aged children are aware of the seriousness of the disease.
- They may have many questions:
 - what is cancer?
 - how did you get cancer?
 - will they get cancer too?

- They are less likely to be anxious if they have known someone who has recovered from cancer.
- They will have heard of Terry Fox, who died from his cancer.
- They may have little or no reaction – they may keep bad news inside.

How you can help

- Keep in mind suggestions for helping pre-schoolers.
- Find the best time for talks, such as driving in the car. This may be easier than a face-to-face conversation with children at this age.
- At this age they are focussed on friends and activities, and mastering skills and rules.
- You can expect that your child will cope through doing and maintaining as much normal activity as possible.
- Talk with your child's teacher about what's going on at home so that the teacher can be supportive to your child.
- Give your children ideas for how they can help out. This will also gradually build important skills for 'normal' life!

Adolescents (13 – 19+ years)

Reactions

- Teens have a greater ability to think abstractly, to intellectualize, and to seek social support.
- Teens are at an age when they are establishing their independence and developing self concept.
- They are coping with the significant demands of school, peer pressure, and trials of experimentation.
- Their peers are very important to them. They may be withdrawing from family.
- They may seem uncaring.
- They may refuse to talk about the cancer or their feelings.

How you can help

- Understand that a lack of reaction is usually your teens' way of protecting themselves from fear, and not a lack of caring.
- Help your teens identify other adults to talk with, and other ways to tell their story.
- Talk over with them whether they want to tell their school, who they would talk to, and what they would say.
- Encourage your teens to carry on with their own routine as much as possible.
- Give your teens suggestions on how they can help at home, but remember not to give them adult duties.
- Discuss ideas for meaningful ways of spending time with the ill parent.
- Reassure your teens that you will seek support from other adults.
- Maintain connection in the midst of confusion, intense emotions, and competing demands.

See

Video Series
*We Can Cope: When A
Parent Has Cancer* (2000).
Inflexion: Newton, MA.

Child Tape

See

Video Series
*We Can Cope: When A
Parent Has Cancer* (2000).
Inflexion: Newton, MA.

Teen Tape

Children's reactions – what they say

What children say

- “It will probably make you feel sad, confused, scared.”
- “It’s normal to feel scared, to have lots of feelings at the same time.”
- “Talking to your parent helps a lot.”
- “It’s not your fault. Your parent does not get cancer because of what you say or do.”

What teens say

- “Sometimes you don’t want all the information. Hearing about what happens with the treatment can be scary.”
- “It’s ok to talk to your parent, to your parent’s doctor, to ask questions.”
- “It’s ok not to talk if you don’t want to.”
- “You can find out in other ways, such as a computer.”
- “It’s important to keep in touch with how you and your parent feel.”
- “It’s not your fault, so don’t feel guilty.”
- “Life will change – sometimes it’s harder, and sometimes better”.
- “You can’t control a lot, but the piece you do have control over is your attitude.”

Chapter 3

Talking About Cancer and Treatment



“The Listener” by Manfred Kuchenmuller

“Cancer is a family affair. Life changes for each member when someone in the family is diagnosed with cancer. These changes can be both challenges and opportunities for everyone in the family and also your friendship circle. Talking with your children about cancer is challenging but full of opportunities too.”

— (Janes, 2005, p.7)

Overview of Chapter 3

- Preparing your children
 - for changes
 - for hospital visits
- Helping your children understand
 - What is cancer?
 - What causes cancer?
 - What is treatment?
 - What are “side effects”?
- Helping your teen understand
- Telling others

Chapter 3 – Talking About Cancer and Treatment

Preparing your children

For changes

Explaining *beforehand* can help your children feel less frightened by the changes:

- Discuss treatment and side effects.
(Children may imagine treatment is bad because it causes side effects.)
- Talk about important *changes*:
 - how treatment may affect how you look or feel, for e.g.
 - your hair will fall out, but it will grow back, or
 - you will feel more tired for awhile
 - how treatment may affect the household routine, for e.g.
 - you may not always be available to drive, or
 - a relative may move into your home to help out
- Keep your children up to date on your cancer, treatment and how it is going.

for hospital visits

A child who wants to see his/her parent should usually be supported to do so. If possible, bring along a familiar adult or older sibling who can leave with your child whenever your child is ready.

Some suggestions for preparing your child when *you or the other parent is in hospital*:

- Describe in advance what the child will see in the hospital, what they will be able to do or touch in the room, and how the parent will be.
- If the parent is sleeping, let the child know that it is ok to quietly talk to or hold the hand of the parent.
- Ask your child about specific fears, such as injections (needles), blood, or a medical crisis.
- After the visit, talk about what part was most enjoyed, most difficult, or most surprising for your child.
- When visits are not possible, encourage other ways of communicating between parent and child, such as cards, drawings, photos, phone calls, videos.

See

Video Series
We Can Cope: When A Parent Has Cancer (2000).
Inflexion: Newton, MA.

Child Tape

See

Hamilton, J. (2001).
When a Parent is Sick: Helping Parents Explain Serious Illness to Children.
Lawrencetown Beach,
Canada: Pottersfield Press.

2. Examples of what to say,
25 – 41.
8. Selected books explaining
and dealing with serious illness,
83 – 124.

See

Slakov, J., & Janes, K. (2004).
Time for Me: An activity book for kids when someone in the family has cancer.
Vancouver, Canada:
BC Cancer Agency.

Chapter 2. About Cancer & its
Treatment, 8 – 25.

Helping your children understand

What younger children say about their parent's cancer:

- “Most kids don’t know a lot about cancer.”
- “It’s kind of confusing.”
- “I found out that cancer is a disease that can be treated.”
- “Your biggest worry is whether your mom or dad is going to die from cancer.”

What you can say to help your children understand cancer and its’ treatment

What is cancer?

Examples of what you can say about cancer:

I have an illness called cancer.

It’s not like a cold or the flu or like feeling bad for a few days.

Cancer is an unusual disease.

There are many different types of cancer.

Some are more serious than others.

Some cancers grow very slowly, others grow fast.

Many cancers are curable and most can be treated.

The doctors say I have an excellent chance of getting better.

With the kind of cancer that I have, the doctors don’t think that I am going to get better.

To learn about cancer and its treatment, your school-aged children will find it helpful to explore the illustrated sections in Chapter 2 of the activity book *Time for Me*. Key words are highlighted, and children are encouraged to write down their questions and ideas.

Examples:

What is a cell?

- The cell is the *building block* of all parts of the body.
- Our cells are tiny – you need a microscope to see them!

What is cancer?

- Cancer is a group of over 200 diseases, where *cells* that are not normal grow and divide quickly.
- The cells may group together to form a *tumour*.
- “Benign” tumours do not spread and are not cancer.
- Cancerous tumours are “malignant” and keep growing, crowding out normal cells.
- Cancerous or “malignant” tumours can spread to other places in the body.

What causes cancer?

- Cancer is caused by *changes inside the cell*.
- These changes cause the cell to grow too quickly and crowd out the healthy cells.
- This may be caused by some chemicals, radiation, air pollution (smoke), certain viruses and other things inside and outside the body.
- There is still a lot we don't know about how cancer begins and what causes it.
- *Researchers* are studying and working hard to find the answers!

Other important questions children ask about cancer:

"If someone in my family has cancer, will I have cancer too?"

- not usually
- inherited cancer is rare
- you can make good health choices to make the chances of getting cancer smaller.
 - Eat healthy foods.
 - Protect yourself from too much sun.
 - Don't start smoking.
 - Enjoy exercise and hobbies.
 - Take quiet times to relax.
 - Have fun! Laughter is healthy too!

What is treatment?

Examples of what you can say about treatment:

Treatment is what makes you get better.

Many cancers can be treated so that the person gets well again.

There are many different types of treatment.

Some cancers are cured quickly and easily by treatment, others are not.

Some cancers can be greatly slowed down.

Sometimes treatment does not work, and people do die.

Sometimes the first treatment does not work well enough, and the cancer comes back.

The doctors may then need to give stronger or different treatment.

Explaining different types of treatment

What is surgery?

- Surgery is an operation where cancer is *removed* by cutting the *tumour* out of the body.
- The person with the tumour goes to the hospital for the surgery, and has special medicine so that he/she doesn't feel any of it.
- A *biopsy* is done when cells are *removed* and looked at through a microscope.
- This is done to see if the cells are normal, or if they are cancer.

What is radiation therapy?

- Radiation therapy is the careful use of x-rays or *rays* from other sources to make the bad cells go away.
- The *rays* can come from a *machine* or from special materials placed in or near the cancer.

What is chemotherapy?

- Chemotherapy uses special medicines or *drugs* to treat cancer.
- These special medicines may be given as pills to take, by special *injections*, or by *intravenous* (I.V.) into the body.
- The *drugs* are carried by the blood to each cell of the body, to reach cancer cells wherever they are.

What are “side effects”?

- “Side effects” of cancer treatment happen because some healthy cells are damaged, usually *temporarily*.
- Some are *visible* – we can see them (hair loss, mouth sores, change in skin or weight, a scar or change in shape of the body).
- Some are *invisible* – we can't tell just by looking at someone (feeling tired, feeling sick to their stomach, wanting to rest more, not being able to work or play normally).

Helping your teen understand

Explaining more types of treatment

What is stem cell transplantation treatment?

- The use of *stem cells* found in either the bone marrow (BMT or bone marrow transplantation) or the blood (PBST or peripheral blood stem cell transplantation) to repair stem cells destroyed by high doses of chemo and/or radiation therapy.
- *Stem cells* (from self or from donors, often family members) are given through an I.V. line.
- Side effects are similar to chemo and radiation therapy, but usually more intense.

What is hormone therapy treatment?

- *Hormone therapy* adds, blocks, or removes *hormones* from the body to slow or stop the growth of some cancers.
- Hormone therapy is given as a pill, through injection, or skin patch, or sometimes surgery to remove glands that make specific hormones.
- Side effects may include feeling hot, tired, change in weight, and change in mood.

How you can help your teen understand

- Tell your teen that you plan to do everything in your power to get better.
- Ask your teen if he/she would like to talk with medical staff, a counsellor, or another teen in a similar situation.
- Invite your teen to attend a medical appointment so she/he can see where you go and have an opportunity to ask questions.
- Suggest that your teen can talk to you about anything, and that the conversation can be returned to again.
- Be available to listen.
- Know that it's ok not to be able to answer a question. Let your teen know you will try to find an answer and get back to him/her.
- Even though your teen may not want to talk about it, keep your teen informed about what's happening with your cancer, treatment, and side effects.
- It's good to set cancer aside sometimes and just spend time with your teen.



National Cancer Institute. (2005). *When Your Parent Has Cancer: A Guide for Teens*.

Chapter 2. Learning About Cancer, 13-16.

Chapter 3. Cancer Treatment, 17-24.

Appendix. Chart A: Monitoring Tests, 66-67.

See

Hamilton, J. (2001). *When a Parent is Sick: Helping Parents Explain Serious Illness to Children*. Lawrencetown Beach, Canada: Pottersfield Press.

2. Examples of what to say, Telling their friends, 34.

See

Video Series
We Can Cope: When A Parent Has Cancer (2000). Inflexion: Newton, MA.

Child Tape

See

Video Series
We Can Cope: When A Parent Has Cancer (2000). Inflexion: Newton, MA.

Teen Tape

and

National Cancer Institute. (2005). *When Your Parent Has Cancer: A Guide for Teens*.

Chapter 8, 47 – 50.

Telling others

Helping your school-aged children with telling their friends

- Although your children may not want to tell everyone, it's important for them to let their friends know what they are comfortable talking about, and what they are not.
- Children at school may feel uncomfortable and not know what to say.
- Sometimes children may say unkind things or make fun of things they don't understand.
- Information about cancer or about your cancer that your child may hear at school, at a friend's house, or in the neighbourhood may be different from what you have discussed. Encourage your child to come and talk to you about it.

What younger children say about telling others

- "Sometimes you just don't want to talk."
- "It's ok to share your feelings with other kids."
- "It's ok too if you don't want to talk about it."
- "Not everyone has a parent with cancer."
- "Your friends may not understand how you feel."
- "You might feel awkward or weird around them."
- "You could say, 'I don't want to talk about it.'"
- "You could say that your Mom is sick."

What teens say about telling others

- "Don't feel obligated to tell everyone everything – or to talk about it."
- "It's ok to have part of your life not about cancer."
- "Your friends may not know what to say."
- "They may ask you difficult questions."
- "They have their own lives."
- "Your friends may say hurtful remarks. You can ignore it, or ask how they would feel if their parent had cancer."
- "You can go to your teacher, guidance counsellor, or principal for support."

Chapter 4 Coping with Change



"Sports" by Liam Lumsden

“Children certainly notice unwelcome changes that cancer brings to families: tension, fatigue, worry, more broccoli and tofu and less junk food. They also describe changes that they enjoy as a result of the cancer experience (for example, more family time together) and learn important life lessons: “You’re the same person on the inside even when you lose your hair.”

— (Janes, 2005, p.7)

Overview of Chapter 4

- Cancer brings changes
- How your children may respond to change
- How you can help your children cope with change
- Signs that your child may be struggling
 - Night problems
 - School problems
 - Fear and anxiety
- When to seek help as soon as possible

Chapter 4 – Coping with Change

Cancer brings changes

Change can result in your children feeling anxious when they

- observe changes in their parent’s health
- experience disruption in their daily lives
- struggle to understand the illness, treatment, and side effects

Your children and teens will adapt better when they are

- informed about events and expected changes in parent’s health
- encouraged to share their fears and concerns
- able to continue their own routines

What children say about changes in the house

- “Things will change – like activities in the house.”
- “It feels weird, doing mommy stuff.”
- “Some kids may say it’s unfair having to do extra chores.”
- “You should take responsibility for helping out.”
- “It’s a good idea to do things you haven’t been asked to do.”
- “Other people helping can make you uncomfortable.”
- “Helping helps.”

What children say about about changes in the parent

- “Some kids are embarrassed when their mom comes to school without a hat or a wig.”
- “Some kids are embarrassed when other kids ask why their mom is bald.”
- “It’s a good idea to keep doing things you like to do, even if your parent can’t always be there.”
- “Keep your head up high – think about what you can do to feel better, rather than what might happen.”



Video Series
*We Can Cope: When A
Parent Has Cancer* (2000).
Inflexxion: Newton, MA.

Child Tape

See

Video Series
*We Can Cope: When A
Parent Has Cancer* (2000).
Inflexion: Newton, MA.

Parent Tape

How your children may respond to change

- Their coping style may not change (some go with the flow, others not).
- They respond in childish ways – children are self-centered.
- Children have scattered reactions.
- They may appear insensitive.
- Children usually can't explain how they are feeling.
- They express themselves through their behaviours.

Children's behaviours show us how they feel

How your children's worries may show up

- Your child may be fearful of entering the ill parent's room.
- There may be changes in your child's behaviour – e.g. a happy-go-lucky child may grow quiet, or your child may become clingy or not want to go to school.
- Your child may ignore you, or walk away when you are speaking.
- There may be little or no reaction – your child may keep bad news inside.

How you can help your children cope with change

You can do a great deal to provide

- support (e.g. join a children's support group in your community, encourage support for your child from other adults, get support for yourself)
- information
- time to focus on your child, even if brief
- encouragement to cope creatively
 - provide drawing and writing activities about change
 - read stories or watch videos together about change
 - have pamphlets, books about change available

Supporting your child

When your child seems afraid

What you can do:

- Reassure your child that many children worry about the same things – who will take care of them, will they get cancer too, their parent looks so different.
- Keep your child informed.
- Reduce surprises.

When your child reacts with anger

What you can do:

- Avoid scolding.
- Be patient, talk in quieter time.
- Reassure your child that it's normal to feel angry when a parent gets sick – the illness causes disruptions, and the child may miss the way things used to be.
- Encourage physical activity.

When your child acts like nothing has happened

What you can do:

- Try to understand and accept your child's need for the security of having a sense of 'normal' and to pretend that nothing is wrong.
- Give your child time to understand.
- Encourage understanding in small bits.

What if you have concerns about your child's behaviour?

When your child's continuing behaviour is not helpful to your child and persistent:

- You may want to seek counselling assistance directly for your child or indirectly for you as the child's parent.
- You may want to increase communication with your child's teacher or school counsellor.

See

Slakov, J., & Janes, K. (2004). *Time for Me: An activity book for kids when someone in the family has cancer*. Vancouver, Canada: BC Cancer Agency.

Chapter 3. About Family.

and

Numeroff, L., & Harpham, W. (2001). *The Hope Tree: Kids Talk About Breast Cancer*. New York: Simon & Shuster Books for Young Readers.

See

Hamilton, J. (2001). *When a Parent is Sick: Helping Parents Explain Serious Illness to Children*. Lawrencetown Beach, Canada: Pottersfield Press.

5. Children's reactions to a seriously ill parent, 63-74.

See

Heiney, S. Hermann, J.
Bruss, K. & Fincannon, J. (2001).
*Cancer in the Family:
Helping Children Cope
with a Parent's Illness.*
Atlanta: American Cancer
Society.

Chapter 3. How to Know if
Your Child Needs Help, 70 – 77.

Signs that your child is struggling

Night problems

What is normal?

For toddlers and young children

- Your children may have regressive changes in their sleep patterns, toileting habits, or thumb sucking.
- They may not want to go to bed alone.

How you can help

- Give your child extra attention, snuggling.
- Use a night-light, leave the doors open.
- Set up a cot in your room.

Consider professional help if

Your child has nightmares nightly, night wandering, or frequently wakes in distress.

School problems

What is normal?

- School-aged children may resist going to school.
- Children and teens may have difficulty with schoolwork or with concentration.
- They may work harder at school to distract themselves from the illness.
- There may be changes in their relationships with peers or teachers (e.g. anger at teachers, acting aggressively with classmates).
- They may have a number of physical complaints.

How you can help:

- Sometimes it helps to just give your child permission to do well and continue as they have in the past.
- Let your child's teacher, school counsellor, or principal know about your illness and ask them to contact you if your child is having problems.
- Help your teen identify others adults to talk with.
- Encourage healthy ways to release feelings, such as physical activities, projects, art, music.
- Encourage healthful habits, such as exercise, rest, and nutritious meals.

Professional help is needed for 'school phobia'

This is a more severe, extreme dread and need to avoid school, expressed through any of the following: inconsolable crying, tantrums, shaking, stomach aches, headaches, nausea, vomiting.

Fear and Anxiety

What is normal?

Fears and worries can vary greatly

- **Toddlers** may be fearful about being separated from or abandoned by their parent.
- **Young children** may be afraid of being lost, of monsters and of bad people.
- **Children** may be afraid of being near the ill parent, of going to the hospital, of being home alone, of the parent's illness and progression of the illness.
- **Teens** may act as if nothing has changed, may refuse to talk about their feelings or the cancer, or may stay away from home more than usual.

How you can help:

- For your **toddlers and young children**, try to keep the daily routine consistent; provide opportunities for holding, hugging, comforting; reassure your children that they have not caused your cancer; encourage your children to express their feelings about the illness by modeling this yourself; help your children release their worries through play, art, music; ask family members or close friends for help in caring for your children when you are feeling unwell.
- For your **school-age children**, keep in mind the above suggestions for toddlers and young children (and remember that children may regress to younger behaviours when they feel insecure); have a regular time each day alone with your child, even if brief; encourage your child to have a trusted adult to talk with; let your children know how they can help.
- For your **teens**, keep in mind the above suggestions for school-age children; encourage your teens to carry on with their own routines as much as possible; understand that your teen's denial may be his way of protecting himself from fear; suggest ways for teens to help out or spend time with the ill parent, but discourage them from taking on adult roles or responsibilities in the family; include teens in decision-making; be available to listen to your teens.

When to seek professional help:

- if fear is a *major* change, and impacts the life of your child, teen or family
- if your child is suffering from 'separation anxiety' or disorder, characterized by excessive anxiety about being separated from you or from home

When to seek help as soon as possible?

If your child or teen shows

- significant behaviour changes, changes in eating or sleeping habits, school problems, or substance taking
- significant fear, anxiety
- depression (there may be a higher risk if there is a history of depression in the family)
- suicidal thoughts (your child or teen talks about wanting to die, or suddenly gives away favourite possessions)

Chapter 5

Finding Ways to Feel Better



"The Seashore" by Aimee Lawley

“Children’s physical and emotional needs include the range of everything from food on the table, to having someone cheer at their sports events, to relationships of love and trust and being there in the hard times. Try to maintain family routines, rules, and boundaries where possible. This will provide a comforting security and stability.”

— (Janes, 2005, p.7)

Overview of Chapter 5

- You can do a great deal to support your child
- Feelings
 - Why is it so hard?
 - What’s important to remember
- How to encourage your children to express their feelings
 - What your children need from you
 - Having a plan
 - Asking key questions
 - What if your child or teen won’t talk?
- Creative conversations – the expressive arts
 - Family activities
 - Especially for teens

Chapter 5 – Finding Ways to Feel Better

You can do a great deal to support your child

- Spend time alone with each child on a regular basis.
- Encourage your child's expression of feelings and concerns.
- Encourage normal activity.
- Take breaks from cancer.
- Give your child choices.
- Give hugs and affection.
- Smile more.

Feelings

“Cancer affects everyone’s feelings in the family. We can have lots of different feelings about things changing. Our feelings may feel stronger at times – such as feeling sad, mad or worried and that’s OK. These feelings are normal.”*

Previously, we looked at the idea that children express their feelings through their behaviours. Parents often find that it can be hard to talk about feelings and about the body with children, and especially with children who don’t want to talk. You may be finding that it can be hard to *understand* your children’s feelings, especially at times when you and everyone in the family may be having strong feelings.

Why is it so hard?

- Children sometimes show the opposite of what they are feeling.
- It is normal for children to have frequently changing feelings.
- It takes time for true feelings to surface.
- Feelings may change over time...children may feel anger, shame, guilt, or a sense of being different on some days, and on other days, a sense of hope or empowerment.
- Children often have difficulty talking *about* their feelings. They may not yet have the understanding or vocabulary, or may be reluctant to do so.
- **Even though it’s hard – ask about feelings anyway.**

* Slakov, J., & Janes, K. (2004). *Time for Me: An activity book for kids when someone in the family has cancer.* Vancouver, Canada: BC Cancer Agency, p.33.

What's important to remember?

- Other things may be going on – not all problems are related to a parent's illness.
- Personalities affect how children deal with stress – more gloomy or worried children need more help.
- It is important to ask children about their feelings, especially those who are quiet or withdrawn.
- You can relieve some of the pressure if you don't have a lot of expectations around your children talking. It takes time.
- **Offering the opportunity to talk can be as important as having a conversation.**

What your children need from you

- your patience! – and your undivided attention
- your permission and encouragement to express their feelings (e.g. "I am really interested in how you feel about that.")
- to have you validate their feelings (e.g. their fears are real, anger is normal and hard to acknowledge)
- to know that others feel much the same as they do
- to feel that support is available

How to encourage your children to talk about their feelings:

Having a plan

- Ask your child to describe what he or she thinks is going on.
- Ask your child to describe some feelings about that.
- Help your child identify his or her feelings (e.g. "It sounds like you are disappointed that I am not well enough to go to your soccer game.").
- Share some of your feelings.
- Reassure your child that she or he is not alone in feeling that way.

Asking key questions (good for all ages)

Two questions

- What is the most difficult part for you?
- What helps you get through this? (Or, what helps you feel better?)

What if your child or teen won't talk?

- Respect your child's or teen's wish not to talk, and need for privacy.
- Try gentle ways to open the door to talking about feelings and cancer – e.g. art, writing, journal writing, music, movies, plays.
- **Remember that children and teens talk when they are ready.**

Creative conversations – the expressive arts

Children benefit from finding creative ways to express themselves – their thoughts, feelings and concerns. Art, music, and writing are some of the natural ways that children express themselves, and they are powerful. The creative/ expressive arts can be ‘therapeutic’ in themselves. Children, including teens, can feel better when they find a way to express who they are inside and outside the family, and what’s important to them. If your children need extra support, counselling that uses art therapy, play therapy or music therapy is especially suitable for children.

Family Activities

You can take an active, playful approach to helping your family share their feelings and experiences. The following activity can be a special way to do this.

“Taking time together”

The ceremony of lighting two “question candles” is a wonderful way to quietly end the day or occasion together. This ritual encourages a quieting time in the family for expressing what’s in the heart and deep listening.

It goes like this:

- Gather your children together in a circle and turn down the lights.
- Have two symbolic “question candles” ready in the centre surrounded by a candle for each member of the family. (Tea lights are fine, small coloured holiday candles are even better.)
- Begin by lighting the two “question candles”, and asking everyone to spend a quiet moment reflecting on their day.
- Suggest that each person quietly asks themselves two questions, such as
 - “What did I enjoy about today?”
 - “What did I find hard?”
- Light a candle for each person as he or she takes a turn to speak...or to be in silence. (It is important that ‘passing’ is ok.)
- Ask someone to ‘count out’ the family – by counting down to zero.
- Then everyone gently blows out the candles together.

You can find lots of ideas for creative family activities in the *Hands-On Tools* sections at the end of each chapter in the book *Cancer in the Family: Helping Children Cope with a Parent’s Illness*.

See

Slakov, J., & Janes, K. (2004). *Time for Me: An activity book for kids when someone in the family has cancer*. Vancouver, Canada: BC Cancer Agency.

p.39.

See

Heiney, S. Hermann, J. Bruss, K. & Fincannon, J. (2001). *Cancer in the Family: Helping Children Cope with a Parent’s Illness*. Atlanta: American Cancer Society.

See

Heiney, S. Hermann, J. Bruss, K. & Fincannon, J. (2001). *Cancer in the Family: Helping Children Cope with a Parent's Illness*. Atlanta: American Cancer Society.

Chapter 3. How to Know if Your Child Needs Help, 70 – 77.

See

Ulman, Doug and Diana. (2004). *No Way, It Can't Be, A Guidebook for Young Adults Affected By Cancer*. The Ulman Cancer Fund for Young Adults, Inc.

Reading together

See Selected Resources for Parents – Books for children at the end of this guide.

Especially for your teens

The following suggestions can help your adolescents deal with stress:

- Stay connected with family and friends.
- Participate in family decision making.
- Stay connected with yourself – find creative ways to express thoughts and concerns.
- Stay active. Find physical ways of releasing tension.
- Find ways to relax and get enough sleep.
- Drink lots of fluids and eat well.
- Avoid risky behaviours.
- Take steps to keep things simple.
- Get help when you feel down.
- Help others when you can.

Writing for health

Although the *No Way, It Can't Be* guidebook focuses on young adults with cancer, it contains some really good information and ideas for helping teens affected by cancer in the family, such as:

- Focusing your emotions
- Many ways of coping
- Writing for health – here are some inspiring suggestions:
 - What gives you hope?
 - What do you want to express to your parents?
 - How are their actions helping or hindering you?
 - Would you like to ask for more help or independence?
 - Is there anything humorous?
 - Is there a way to express gratitude to your parents?

Chapter 6

The Road Ahead: Helping Children Thrive



"Rainbows" by Heather Mah

“Is there such a thing as being “too honest” or giving too much information? This is one of the places where your love and knowledge of your own child’s needs and strengths comes in. We find this quote helpful: “Being honest does not mean telling everything...What it does mean, is never telling anything but the truth.*”

— (Janes, 2005, p.7)

*McCue, K., & Bonn, R. (1994).
How to Help Children through a Parent’s Serious Illness.
New York: St. Martin’s Press, p.10.

Overview of Chapter 6

- Survivorship – a new normal
 - What you can do
- Managing Uncertainty
 - Helpful strategies
- Recurrence
 - Suggestions for helping children cope
 - Examples of what you can say
- Breaking the news of declining health

Chapter 6 – The Road Ahead: Helping Children Thrive

Survivorship – a new normal

The time after treatment is often described as “living in limbo”. It is typically a time of uncertainty, for the recovering parent and family too. Everyone may be feeling many different emotions – glad that it’s over, yet missing some of the changes too. Emotions that have been put aside during the demands of treatment may surface, especially during follow-up medical appointments or anniversary days that mark the journey.

As much as you may have looked forward to this time as a celebration and relief from the rigours of treatment, it can be a challenge for all family members to find a new sense of normal.

You (and your children) may wonder:

- Will the cancer come back?
- Will I survive?
- Will life ever be the same?

A time for recovery

Now that treatment is over, the family will likely expect the ‘old parent’ back again. As a recovering parent, however, you are likely tired and lacking energy at times. You may be questioning former beliefs and values, and re-evaluating where to go from here. What you need is time to take care of yourself, and this usually takes a reorganization of family time.

Caring for yourself physically (e.g. exercise, diet, follow-up appointments, relaxation exercises), emotionally (e.g. journal writing, support group, time with friends), intellectually (a new book, a new class) and spiritually (religion, meditation, nature) can benefit the whole family. As you grow stronger, your children will learn about living and healing.

What you can do to help your family find a ‘new normal’

- Realize that it takes time.
- Offers of support may dwindle, once the crisis is over. Ask for help – let family and friends know what you need, and tell them you value their continuing support to help you get better.
- Though they may protest, teens can continue to help with more mature tasks such as meal preparation, shopping, and driving, while pre-teens can sort laundry, vacuum, and walk the dog.
- Schedule breaks for yourself from household duties and children.
- If you find that you are anxious or depressed, or taking your anger out on your family, discuss this with someone who can help, such as your family doctor. Check with your local cancer centre for counselling and supportive resources in your community.
- Take time for opportunities to enjoy family routine together (e.g. breakfast out on Sundays, a weekend family walk, ‘family night’ when everyone takes a turn planning dinner and an activity for the night).
- Even if you have tried this and it hasn’t worked, bring the family together on a regular basis to keep everyone in the loop – focus on sharing information and discussing plans for the future.
- If you haven’t already set up such a routine, spend time alone with each child (including teens) doing something pleasurable, or just being together. Having breaks from cancer and the demands of family on a regular basis can be healing for both parent and child.

Managing Uncertainty

“Regardless of prognosis, all people with cancer need to learn how to manage the uncertainty of living with cancer. The best a parent can do is to acknowledge the possibility of death while focusing on living each day. Many people with cancer say that once they acknowledge this, they are better able to get on with life.”*

Fears may resurface after treatment ends

Your children may remain confused and fearful that the cancer is recurring when they see that you are tired and irritable, and still don’t look like your old self. They observe that you are anxious before a follow-up visit. If they haven’t done so already, they may worry that their well parent will become ill too. Your children may become preoccupied with their own health, especially teens.

* Heiney, S. Hermann, J. Bruss, K. & Fincannon, J. (2001). *Cancer in the Family: Helping Children Cope with a Parent’s Illness*. Atlanta: American Cancer Society, 141.

Helpful strategies for living with uncertainty

- Keep talking with your children. Tell them it's ok to ask questions.
- Tell them that worrying is normal for everyone in the family when treatment ends.
- Ask your children what they may be worried about or afraid of.
- Ask if your child has any specific worries about what would happen if the cancer came back or their parent died.
- Acknowledge how hard uncertainty is.
- Reassure them:
 - You will let them know of any changes to your health.
 - You intend to take the best possible care of yourself so that you can hopefully live for a long time.
 - You have a back-up plan for their care in the worstcase scenario.
 - You hope they will share their worries with you, and you will help them find ways to ease their worries.
 - You hope your child will be able to put aside their worries and continue with their activities and life as though it will all work out well in the end.

Managing anger

- If you find that your children are angry (e.g. fighting with peers or siblings, temper tantrums, lashing out or shutting down), talk with them about their behaviours.
- Ask what specifically makes them angry, whether they blame you for
 - getting sick
 - not having enough time for them
 - not getting back to the way things were
- If your children are blaming your smoking or diet or lifestyle for causing your cancer, tell them you also feel angry or guilty for not trying harder to make changes, but that you can't undo the past, and with your family's help, can work towards making good health choices.
- Tell your children that it's been hard for the family, and that it's normal for everyone in the family to feel frustrated or angry at times.
- Encourage your children to vent their feelings in other ways, such as physical activities, pounding clay, drawing, or writing out their anger.

Recurrence

Suggestions for helping your children cope

- Encourage your children's understanding of recurrence while nourishing hope.
- Whether it has been a long or short time since your original diagnosis, you can say that the cancer has come back.
- Depending on your treatment plan, explain that you will need to be treated again, with different or stronger treatment.
- Discuss what is likely to happen and what side effects are expected.
- Discuss how treatment will affect their lives, what changes in family routine they can expect.
- Acknowledge that everyone in the family may feel more worried and unsettled now, and ask for suggestions to help the family adjust to the changes.
- Let them know they can ask questions anytime they are ready, and that there are no "dumb" questions.

Helping children deal with recurrence

The most feared question, "Are you going to die?" may come up now, if it hasn't already. Even if it does not come up, kids will wonder anyway, or will have heard things from others that may not be accurate. Children need to know that their parent can talk with them about death, so that everyone can set this aside and get on with living. It's important to acknowledge the possibility of dying, and to be realistic yet hopeful.

Examples of what you can say

- Some people with recurrence of this type of cancer get better and others don't.
- I can honestly say I don't know if I am going to get better.
- It's possible I could die, but I'm not doing that right now.
- Right now the doctors expect that I will get better.
- I am planning on getting better and I am trying my best to do so.
- Let's give treatment another chance.
- We hope the treatment will work.
- I'm not sure how I will do. It depends on how I respond to treatment.
- If this treatment isn't working, we hope there will be a new treatment that does work.
- I will let you know if it looks like the treatment isn't working.
- We will tell you if I'm getting worse.

See

Hamilton, J. (2001).
*When a Parent is Sick: Helping
Parents Explain Serious Illness
to Children.*

Lawrencetown Beach,
Canada: Pottersfield Press.

Addressing the future, 12–13.
Explaining...What may happen in
the future, 31–33.

Calling on family and friends

- You may need to ask friends and family for extra support during this period, to help your children continue with their routines, and to help with your younger children.
- Your younger children may need more attention at a time when your reserves may be exhausted. Children's behaviours that express their worries may appear as new or renewed difficulties, such as separating from their parent, paying attention, or going to the toilet.
- It may take a special effort for you or another adult to connect with your teens about what is happening. Teens are normally focused on their lives outside the family.

Breaking the news of declining health

"...Again, tell your children that you will be honest with them if it looks like you will not survive. This may be extremely difficult or impossible for you to do. This is very understandable, and if so, your spouse or partner may be the one to have this conversation."*

Even if you accept the real possibility of dying in the near future, you can at the same time have reason for hope, if there is any chance for your improvement. You will need to decide how hopeful you want to be.

Prepare your children with graduated levels of information about your declining health.

Examples of what you can say

- You will keep them informed about how you are doing.
- You have a very serious kind of cancer. Many people with this kind of cancer die, but some get better. You hope you are one of those who get better.
- You don't know if you are going to die from this cancer. You hope not.
- You will tell them if you are getting worse.
- You will let them know when treatment is no longer working.
- You will let them know if you are not going to get better.
- You are not dying now.
- You are not dying until you are dying. You will tell your children when it looks like this is going to happen.

Your children and teens will most certainly feel upset by the news of your worsening condition. But they will have a better chance of adjusting to and coping with the changes and losses associated with your declining health, if you talk to them about this. You will then have a chance to give your children an important opportunity to express their love and to say good-bye.

* Heiney, S. Hermann, J. Bruss, K. & Fincannon, J. (2001). *Cancer in the Family: Helping Children Cope with a Parent's Illness*. Atlanta: American Cancer Society, 141.

See

Chapter 6. Helping Children Deal with Recurrence, Progressive, or Terminal Illness, 133 – 150.

See

Harpham, W. (1997). *When a Parent Has Cancer: A Guide to Caring for Your Children*. New York: Harper Collins.

Helping Your Children Live With Uncertainty, 87-93.

See

Hamilton, J. (2001). *When a Parent is Sick: Helping Parents Explain Serious Illness to Children*. Lawrencetown Beach, Canada: Pottersfield Press.

Chapter 9. When a parent is dying, 95 – 100.

Chapter 10. When a parent dies, 101-106.

What children need to help them cope with a parent's medical crisis or declining health

- to be informed about the medical situation
- to have their questions answered honestly
- to know why their parent may look different
- to remember that the ill parent is the same parent he or she has always been
- to remain emotionally connected and included
- to know they can help by staying connected
- to know that efforts will continue to help their parent
- to know that additional support is available to help them cope
- to know they are loved

The dying process is a deeply personal experience for every parent and those close to them. It is different for all involved. If the needs of your children and teens are cared for during the most difficult phase of a parent's illness by the most important people in their lives, those who love them most, you can help your children adjust and thrive, now and in the future, with their immeasurable loss.

Selected Resources for Parents



“My House” by Mattison S. and Linda S.

Selected Resources for Parents

Books for Parents

Heiney, S., Hermann, J., Bruss, K., & Fincannon, J. (2001). *Cancer in the Family: Helping Children Cope with a Parent's Illness*. Atlanta: American Cancer Society.

Outlines valuable steps necessary to help children understand what happens when a parent has been diagnosed with cancer. Covers all ages from newborns to teens and offers suggestions for answering difficult questions.

McCue, K., & Bonn, R. (1994). *How to Help Children Through a Parent's Serious Illness*. New York: St. Martin's Press.

A supportive, practical guide through all the many turnings of how children respond to a parent's serious illness. Written by a child life specialist, it will help parents and caregivers to face the mental and emotional stresses, and come out healthy, no matter what the parent's medical outcome.

Harpham, W. (1997). *When a Parent has Cancer: A Guide to Caring for Your Children*. New York: Harper-Collins.

A book for families written by a mother, physician, and cancer survivor offering clear, direct and sympathetic advice. Suggests concrete ways for all family members to work together to achieve equilibrium in the midst of the chaos that serious illness can create.

Hamilton, J. (2001). *When a Parent is Sick: Helping Parents Explain Serious Illness to Children*. Lawrencetown Beach, Canada: Potterfield Press.

www.pottersfieldpress.com – to order phone toll free 1.800.646.2879

A guide for parents and others with some ideas and examples of how to talk to and respond to children throughout the illness trajectory, including bereavement.

Videos

Kids Tell Kids What It's Like When a Family Member has Cancer. 1998. Cancervive Inc.: Los Angeles, CA.

Designed for parents and kids to watch together.

Part two: Kids share their stories about what it's like to have a mom or dad with cancer. These kids discuss feeling scared that their mom or dad might die, or embarrassed when their parents lost their hair. They share how joining a support group, talking to a friend or asking their parent's questions about cancer made them feel better.

My Mom Has Breast Cancer: A Guide for Families. 1996. KidsCope. www.kidscope.org

This video presents children's responses to the diagnosis of their mother's breast cancer. The children and mothers interviewed describe their reactions and feelings and how they learned to cope during this experience.

Talking About Your Cancer: A Parent's Guide to Helping Children Cope. 1996.

Fox Chase Cancer Centre.

Video for parents on talking to their children about their cancer.

We Can Cope. 2000. Inflexxion: Newton, MA.

The *We Can Cope* (2000) video series emphasizes the growing notion that cancer is, indeed, a family illness. The three-tape (Child Tape, Adolescent Tape, Parent Tape) series provides a necessary complement to the inevitably difficult parent-child talk about a parent's cancer diagnosis. The child and teen tapes are visually stimulating, developmentally appropriate and the content is geared toward the specific needs and interests of the two age groups. The parent tape is eloquently narrated by Dr. Wendy Harpham and provides practical advice for implementing many of the suggestions contained in Harpham's (1997) book *When A Parent Has Cancer*.

Living With It. Mother to Daughter. Women Living With Recurrent Breast Cancer Share Their Experiences. 2002. Susan Nessim/Cancervive. www.cancervive.org

Four women with recurrent breast cancer share their deepest concerns about the impact their illness has had on their teenage daughters. This video was developed to facilitate communication between mothers and daughters.

Pamphlets

For Parents

American Cancer Society. 1993. *After Diagnosis: A Guide for Patients and Families*.

American Cancer Society. 1986. *Helping Children Understand: A Guide for a Parent With Cancer*.

Canadian Cancer Society. 1997. *Talking With Your Child About Cancer*.

For Adolescents

BC Cancer Agency. 2004. *Getting through: A Student Resource for Sorting Out School When Cancer Affects the Family*.

BC Cancer Agency. 2004. *Getting through: A Teacher Resource for Understanding Students Affected by Cancer in the Family*.

Canadian Cancer Society. 1995. *When Someone You Love Has Cancer*.

National Cancer Institute. 2005. *When Your Parent Has Cancer: A Guide for Teens*.

For Kids

American Cancer Society. 1987. *It Helps to Have Friends: When Mom or Dad has Cancer*.

Sources of General Information about Cancer and Its Treatment

Helpful Websites

Breast Cancer Action: How We Told Our Children: In our own words Part II. www.bcans.org Breast Cancer Action Nova Scotia, 2001.

Griefworks BC – Kids Home. www.griefworksbc.com

Kidscope. www.kidscope.org Information to help families better understand and cope when a parent has cancer.

Kids Konnected. www.kidskonnected.org Website for kids who have a parent with cancer, including a chat room.

Hurricane Voices Breast Cancer Foundation. www.hurricanevoices.org The website includes a comprehensive family reading list, including brief synopses.

Books for Children

Goodman, M.B. (1990). *Vanishing Cookies: Doing OK When a Parent has Cancer*. Downsview, Ontario. The Benjamin Family Foundation.

For 7 – 12 year olds and their families; to help them share feelings which may be difficult to discuss; question and answer format; colourful, appealing illustrations.

Harpham, W. (1997). *Becky and the Worry Cup*. New York: HarperCollins.

Paperback with black and white illustrations; written by a doctor who developed cancer; 48 pages of text which would be good for parents to read to children who like to listen to long stories; included in a pocket of the hardback edition of Harpham's *When a Parent has Cancer*.

Numeroff, L. & Harpham, W. (2001). *The Hope Tree: Kids Talk About Breast Cancer*. New York: Simon & Shuster Books for Young Readers.

Drawn from real stories by kids 5 – 12 years old about mothers with cancer. The Hope Tree focuses on ten key topics that often affect families dealing with illness. Animal characters are used to provide insights and advice in a comforting format.

Kohlenberg, S. (1994). *Sammy's Mommy Has Cancer*. New York: Magination.

Colourful pictures, brief text; mother goes through treatment, loses hair, etc; suitable for young children; paperback.

Slakov, J. & Janes, K. (2004). *Time for Me: An activity book for kids when someone in the family has cancer*. Vancouver, BC: BC Cancer Agency.

A workbook format in which children 6 – 12 years old are encouraged to learn about cancer and its treatment, changes and feelings in the family and ways of feeling better.

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“Twinkle, Twinkle” by Katrina Leming and Glen Stojcic

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