

## Quick Links

What do I tell the Children?

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Cancer Society

*Living with Cancer*

## What do I tell the children?



*A guide for a parent with cancer*

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## Introduction

This booklet outlines steps you can take to help children understand what's happening to you and help you through this difficult time in your family or whanau's life. Although the booklet may sometimes speak about a parent with cancer, the material is relevant for anybody who is a significant family member or caregiver/kaiawhina.

The booklet is divided into three parts. The first critical step is talking to children about your cancer. This section covers the why, who, when, how and what, to tell a child. There are some actual examples of what a parent or caregiver might want to say. It includes typical responses of children according to different ages and developmental stages.

Section two, Coping with the changes, will help you to think about the children's thoughts and feelings. It suggests things to say and do, depending on the ages and developmental stages of the children. It considers some issues you may want to consider if you are not going to recover, and how you and other adults can help children face the future. It includes comments on the value of discipline along with warmth.

The third and last section is about sharing experiences, good and bad. It contains suggestions on activities for the family, particularly things to do if a caregiver is in hospital. The emphasis is on positive approaches that should help families strengthen ties and demonstrate their love for each other.

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## Talking to children about your cancer

### *Why should children be told?*

- A child has a right to know about anything that affects the family, as cancer does.
- Children know something is wrong. If you protect them by saying nothing, they may have fears which are worse than the real situation.
- Not talking about cancer may suggest it is a subject too terrible to be discussed. There is a hopeful side. You would not wish your children to have an abnormal fear of cancer or illness.
- Children may find out the truth from someone else, or get misleading information from TV or other sources.
- Children can feel isolated if they are not told. They might feel they are not important enough to be included in a family matter.
- Children are good at noticing things but poor at understanding what they mean. For example: "Grandad died in hospital. Now Dad has to go into hospital. He is going to die too". Or, "I was cross with Mummy when she told me to pick up my toys. Then she was ill. Maybe I made her ill".
- Children who know the situation can be a comfort to you. You won't need to feel secretive and isolated in your own family.
- Children have an amazing ability and capacity to deal with truth. Even very sad truths will relieve the anxiety of too much uncertainty. We cannot make them not sad, but if we share our feelings and give them information about what is happening, we can offer them support in their sadness.

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- Coping with cancer in the family can be an opportunity for children to learn about the body, cancer, treatment and healing. They can learn about feelings and the strength of the human spirit in difficult times.

### *Who should tell the children?*

- You should – if you think you can keep fairly good emotional control. It is all right to cry. Seeing you cry gives children permission to cry too, though you will not want to be unduly upsetting. You will know in your heart if you can be the one to tell them.
- Alternatively, a close relative could do it, or your doctor or other appropriate professionals.

### *When should I tell the children?*

- After being diagnosed – explain what is wrong.
- When you are being treated – explain how you are treated, side effects if any, any changes in treatment, and whether things will be different at home or in how you feel.
- After you finish treatment – explain to the children that you will tell them about your health and about any changes.
- Be willing to talk whenever a child asks questions or seems concerned about your condition.

### *How should I tell the children?*

- At first you may want to talk to children individually. They may need to know different things because of age or development level. Later, it might be comfortable for you to talk about some things together.

- You may want to practise what you will say and anticipate what questions the children will ask (see later in this booklet).
- You will want to talk in a language each child understands.

### *How much should I tell the children ?*

- Children need to be told information they can understand.
  - Tell them what has happened.
  - Explain what will happen next.
  - Leave them with feelings of hope that even though you are upset now, there will be better times.
  - Assure them they will still be loved and cared for.
- Listen to them – it lets you know what they can cope with.
  - Answer their questions simply.
  - Ask them what they think cancer is.
  - Ask them if they are worried about you.
  - Correct any wrong ideas they may have.
- Let them know feelings as well as facts.
- Some don't's:
  - Don't lie.
  - Don't trouble them with frightening medical details, money worries (except as it will affect them), test results that are not in yet, etc.
  - Don't make promises you may not be able to keep. (Say "I think I will be able to ..." or "I'll try to...").
  - Don't be afraid to say "I don't know".
  - Don't push children to talk.

- Some ways to say things:
  - "I have an illness. It is called cancer. The doctor is giving me medicine to help me get well. Sometimes I will feel sick or tired and sometimes I will feel fine. Dad/Grandma/Auntie will help me take care of you until I feel better."
  - "Being ill makes me feel sad. You are a help, but it's all right for you to feel sad (or angry or happy or whatever). Our feelings change but love is always there".
  - "There was something growing in my body that wasn't supposed to be there. It is called cancer. The doctors took it out in the operation I had. Now I will have treatment so it doesn't grow back. If you have any questions about cancer, you should ask me. Sometimes you hear frightening things about cancer. I will tell you what we know about my cancer."
  - "The cancer is trying to grow again. That makes me angry and sad, too. I have to take very strong medicine (or have another operation or radiotherapy) to try to get rid of it. Doctors know a lot about taking care of people when this happens. We are doing the best we can. We think it will work."

## *Different ages and stages*

Helping children to understand your experience with cancer needs sensitivity and a good sense of timing. Children may go through the stages you are going through – disbelief, anger, reorganisation, hope and acceptance. They may have special needs because of their ages. During your illness, their needs may change.

### **Under-fives**

The youngest children fear separation, strangers and being left alone. If you are in hospital, arrange for a familiar person to stay with them. Talk to them – assure them you are coming home from hospital soon and that you think of them when you are apart. If they come to visit you, suggest they bring a well-loved toy with them.

Young children feel they have magical powers and what they wish will come true. They may feel guilty that the person who cares for them is ill, or about having bad thoughts about a parent or caregiver. Assure them that nothing they have done or said or thought could cause your illness.

### **Ages 6-11**

Children between six and eleven may be unduly concerned about a parent's or caregiver's health. It is important not to put pressure on them or worry them with details. Let the children's teachers know about your condition promptly, and perhaps the school nurse as well. Their suggestions and understanding will help if there are any problems.

Disturbances in eating, sleeping, schoolwork and friendships may happen. Children at any age may start behaving like younger children. Sometimes it is just their way of saying, I'm here too.

### Teenagers

Teenagers have an especially hard time – adolescence is not an easy time in any case. Their emotions are sometimes complicated and troublesome. They may find it hard to talk to you or show you how they feel, and at times their behaviour may be difficult for everyone to deal with. At a time when they are often struggling to be grown up they may feel that it will be seen as childish to show emotions or to ask for help. Not talking may be their way of trying to appear strong for you, or may happen because they are worried that they will be misunderstood. It may often help to reassure them that talking about their feelings and worries is a positive way of coping and is how adults often deal with stressful situations. If they are finding it hard to talk to you, encourage them to talk to someone close who can support them, such as a relative or family friend.

Your illness may mean that they are asked to take on more responsibility than they had before. This can be a positive and even growing experience for them if they feel their efforts are helpful and recognised. But difficulties can arise if they feel overburdened with responsibility to the point of not having their own needs met. Teenagers need to be included and consulted as adults but will continue to need guidance, support and reassurance.

Keeping to normal rules you had before your illness is also important. They need to know that a normal life matters even more than before.

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## Coping with the changes

Sometimes all that is needed is time to adjust. At other times, there are various things you can say or do to help.

### *The unknown and the uncertainties*

What makes cancer especially difficult are the many unknowns. Living with uncertainty is part of having cancer. There are some questions you will not be able to answer. Accept that – and help your children accept that fact also. Find out all you can to make the unknown more familiar.

### *Changes*

Everyone in your home will be affected by your cancer, even if they don't all show their feelings. There may be changes in your appearance and there may be changes in what you are able to do.

You will want to try to keep things as normal as possible. Be there as much as you can for the family's sake. Keep as many things as you can the same.

A daily routine is important. See that the necessary things get done. Another family member may have to take over some of the things you usually do. Children will learn that this is part of what it means to be a family. Get outside help if necessary, especially if you have side effects from repeated treatment that could worry young children.

It is also best, if possible, to have the same person helping, especially when there are young children who need consistent care.

Children are often more able to accept body changes than adults. Give a brief explanation of why you look or feel the way you do, and let it go at that. If you are not upset, the chances are

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your child won't be and he or she will accept the changes easily. You may well find yourself a subject of gossip among the local children. This may be your chance to teach them to understand something about cancer, if you are up to it! On the other hand, your children may not want to admit that anything has changed in your home. Let them know you are willing to talk to their friends if they want you to.

Be flexible – sometimes changes make it necessary to declare a state of emergency when everyone has to adjust their plans. Try to be relaxed if changes must be made, and involve children as much as you can in the new plans. Children respond differently and have different needs at different ages – (see the section on different ages and stages).

If you're finding problems persist, let your GP and the hospital know. Don't hesitate to ask for professional counselling. It may be possible for the whole family to be counselled together.

Try and find out if there are any cancer support groups in your area as it can be very helpful to talk to someone in a similar situation. Ask your local library if there are any videos or books that may be helpful. Some recommended books are listed at the back of this booklet.

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## *Discipline*

Discipline may be difficult because children can behave badly in order to get the attention they feel they are missing. But a breakdown in discipline can convince a child that something is very wrong at home. It is important to set consistent and familiar limits and find ways to enforce them – for your sake and for theirs. Communicate your understanding, love and acceptance of the children but not their misbehaviour. Reward good behaviour and let them know you especially appreciate co-operation now. Remember it wasn't always perfect before.

## *Children's feelings*

If you never show how you feel, the chances are they won't either, but covering up strong emotions is like sitting on a time bomb. A child can become frightened of his/her own feelings instead of accepting them as normal.

Of course you are sad about what has happened. Don't be afraid to express it. If you can let the sadness out and cry together, everyone will feel the tension ease.

### **Children may feel other things:**

- Some children will feel sorry for themselves when the person who cares for them is ill, then feel guilty because they think they should feel sorry for the parent or caregiver
- Some children will try to make up for those guilt feelings by being super good and setting impossibly high standards for themselves.
- Some children will cling to you too much, afraid something will happen if they are not there.
- Some children will withdraw from you, unconsciously trying to become more independent in case something else happens to you.
- Some children will resent the fact that they need to help you when the opposite was true before.
- Some children will laugh and behave badly to cover up their real feelings or their lack of understanding (especially in strange situations).
- Some children will pretend to be ill to get attention or because they want to be with a parent. They might make a big fuss about a minor illness.
- Some children will be afraid they'll get cancer too.

These things will pass with time, but let the children know that you understand and accept them as they are.

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## *If you're not going to recover*

It is important to balance hope with reality. There may come a time when the reality is that you are not going to recover. Death and dying are not talked about openly in our culture, and it may be difficult to face the knowledge that you are going to die. It will be difficult for your family and children too – facing it together and allowing them to be part of that process is likely to help them face the future.

The more prepared you are to talk about what is happening, the more at ease you are likely to be discussing it with the children. If you find you can't talk about it, there are others who may be able to help. These include a trusted family member, a friend, doctor, nurse or religious or spiritual person who knows your family and your values and whom the children know and trust.

Children under the age of ten, and especially children under the age of seven, have difficulty understanding the concept of death. In some cases professional help may assist. Child psychologists or psychotherapists trained in play therapy are very helpful for the younger age groups.

Children often know much more than we imagine, and need to be given permission to talk about it. We need to speak in a language that they will understand, avoid jargon and use open, honest, direct communication. Even more importantly, we need to listen. Sometimes children may use symbolic language. For instance, "I'll stay here and look after you" might mean "I'm frightened to be on my own".

What has been written previously in this booklet applies equally here. However, there are other considerations:

- What are your priorities?
- How do you want to spend your time?
- How might the children be involved?

You may not feel well or strong, but that might not matter too much because it will be the quality of time rather than the quantity that the children are likely to remember.

Maybe the children can help to look after or care for you. Without overburdening them, you can help them feel included and special if they can do small things for you.

If you are able you may like to do things together. (see next section 'Sharing experiences' for some suggestions).

Children learn about solitude, intimacy and companionship by being quietly in someone else's company, being together without necessarily needing to talk, e.g. reading, drawing, sewing, making things.

Your children will probably ask questions:

### **What about me?**

- What will happen to me?
- Am I going to die too?
- Will others whom I love die too?

### **What about you?**

- Will I see you again?
- What happens to your body?
- Where do you go?
- Does it hurt?
- Why does it have to happen?
- Is it a punishment?
- Is it my fault?

It may help to expect questions and to think about how you want to respond in your own way. There is no right way – it will depend on your philosophy of life and beliefs. However, perhaps what is most important is that your child feels able to voice his/her concerns and questions, and feelings are taken seriously.

**Here are some things you could say in answer to:  
"What will happen to me?"**

"Daddy/Mummy/Granny etc., will still be here and will look after you. Daddy will take you to school and Auntie Jane will collect you after school and you will stay with her until Daddy comes home and collects you. Uncle Tom will take you to swimming/football etc."

Children need very specific answers to this question. They need to know where they will live and with whom, and who will do all the things you have been doing for them.

**"Will Daddy/Granny die, too?"**

"Everybody has to die sometime, but Daddy/Granny are all healthy at present and there is no reason for you to think that they will die soon. What is it that you are really worried about?"

**"What about you?"**

You may feel comfortable talking about your death with a child. Many parents or caregivers find this too painful. If you feel like that then ask a friend or a professional who knows your child and you – possibly a teacher – to talk to your child.

The main thing to remember about telling children is that they need clear, simple, truthful information repeated as things change.

**Other things you could say**

"It's no-one's fault. Nothing you did or said made me get ill".

"Cancer is not catching. Most people die when they are old and their bodies get worn out. It is very unusual and very sad for someone young to be so ill that the doctors cannot make them better."

"Although Mummy is dying, the family will stay together; we will look after one another. Mummy's love will always be with us and will help us."

Children need to know what will change in their family life and why, and the reassurance of knowing that some things will stay the same: "We will still go to the football match on Saturday."

"When someone dies their body is no more use to them. It is an empty shell. It cannot feel pain, happiness, hunger or sadness. A dead body has stopped working for ever. It is not like being asleep. A dead body cannot wake up again. A dead body is usually put in a special box called a coffin and either buried in the ground or burnt in a special oven called a cremator, this is known as cremation. A funeral is a time when everyone who knew Mummy will get together to remember her. Some people will cry, everyone will think a lot about Mummy. There will be special prayers and hymns/songs. We will play Mummy's favourite music. Uncle Tom will talk about Mummy. You can choose a poem to be read if you would like to.

"Everyone is very sad that Mummy is dying. Sometimes it makes us all feel very angry too. It seems so unfair. It is no-one's fault. It is because of Mummy's illness."

Remember – no one knows exactly when someone will die. Children need to have gradual explanations about what has happened and why, and what may happen next. When death is very near, children may need to know that: "We don't think Dad will live much longer now". "We think he will be weaker each day now."

Older children may want to know something about how death will occur and may be reassured to know that: "Dad will become more deeply unconscious, his breathing will get much slower, with big gaps between the breaths, until eventually it stops altogether. Dad's heart will stop beating and he will be dead. It will be quite peaceful."

**Afterwards**

You can help children face life afterwards by preparing them for the future without you.

For younger children a letter or video from you to be read/viewed later can be very positive.

You can make a photo album or scrapbook with photos chronicling the child/children's babyhood and childhood, with messages about how you felt about the child at the time the photo was taken.

Children can be involved in the funeral and older children can make choices about their part in it. Perhaps you could make some plans beforehand, especially with older children.

**Who is going to care for the children after your death?**

If you are a single parent or caregiver, it is important to sort out who will care for your children after your death. You may want to talk to a lawyer to ensure these details, along with your will, are taken care of properly.

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**Sharing experiences, good and bad**

However long you may have to live, time with children can be precious. It is difficult to enjoy quality time with them when you are feeling the effects of cancer or its treatments. Some of these suggestions may help.

**Being together**

If you need to, think of things to do together that do not require much energy – read, watch TV together, write a story about your family and share it with them. Have plasticine or play dough and other creative materials to use to work out some frustrations that you and the children share.

Plan for laughter. Laughter is good medicine for all of you. You are still going to have fun together. You may enjoy each other even more.

Here are some additional activities that you may want to try.

**In hospital**

If you are in hospital, children can:

- Visit in the room, or day room. Ask the ward staff about any other facilities, e.g. use of the canteen.
- Make phone calls.
- Share tape-recorded messages.
- Exchange pictures or photographs.
- Exchange presents. You can pack small gifts to give children when they visit you.
- Children may be interested in all the mechanics of a hospital. Explain how the bed works, the call button, meal service and all the different people who are there to help you.
- Explain procedures if your child shows interest or concern, or if you feel you can help him/her feel more comfortable and secure about your being in the hospital.

**At home**

- If you are at home, even a small child can be involved in bringing meals, or the paper or books to read. Do as much as you can yourself so children don't begin to resent running your errands. Allow for them to have enough free time for themselves.

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- Read a book together about the body. Point out where the cancer is and what is happening physically.
- With younger children, role play. Act out what is happening to you by using a doll. Use other dolls for other members of your family. Children often express what they are really feeling in their play. Listen.
- Get together with other parents and families who are coping with cancer. Arrange for your children to meet other cancer survivors.
- Share meaningful poems and songs with your children.
- Make up or find a slogan to help all of you. Make posters, mobiles or badges using the slogan for inspiration.

### Benefits of sharing

You can make a difference by how you choose to respond to the fact of your cancer. Any positive points for your family are important.

- You may be spending more time with the children and actually feel closer to them. Sharing emotions can really strengthen the bond between parents or caregivers and children.
- Children can grow in their ability to face other difficult experiences in life. They can grow in independence and self-confidence. They may become more responsible. They may become more sensitive to the needs of others and more able to understand and love another person.

Cancer can bring out the best in people. You can take pride in their ability to deal with problems and find new solutions.

Your whole family may discover reserves of love and inner strength that will enhance the rest of your life together.

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## Recommended reading list

### Books for parents

**When a parent has cancer – a guide to caring for your children**

Wendy Schlessel Harpham. Harper Collins: New York, 1997

**How to help children through a parent's serious illness**

Kathleen McCue with Ron Brown. St. Martins Press: New York, 1994

### Books for children

*Early illness:*

**Sammy's Mommy has cancer**

Sherry Kohlenbert. Magiraham Press: New York, 1993

**What about me? for children when a parent has cancer**

Patient Services: Anti Cancer Foundation, September 1994

**My Daddy's cancer –an interactive book for children**

Cindy Klein Cohen John Heiney. Promise Publications: Bloomfield Hills, 1999

**Moms don't get sick**

Pat Bruck. Melius: Aberdeen, 1990

**"What is cancer anyway?" Explaining cancer to children of all ages**

Karen L Carney. Barklay and Eve Series Book 5, USA, 1999.

**When someone in your family has cancer**

National Institutes of Health. National Cancer Institute, USA (also available at <http://cancernet.nci.nih.gov/peb/family>).

**Kemo Shark**

H Elizabeth King Kidscope Inc: USA, 1995

(also available at [www.kidscope.org](http://www.kidscope.org))

**The paper chain**

Claire Bake, Eliza Blanchard and Kathy Parkinson. Health Press: USA, 1998

**It helps to have friends when Mom or Dad has cancer**

American Cancer Society, USA, 1987

**Michael's Mommy has breast cancer**

Lisa Torrey. Hibiscus Press: USA, 1999

**My Mum has cancer**

Julie Powell. Child Cancer Foundation Central Division

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**Once upon a hopeful night**

Risa Sacks Yaffe

*Later on:***It must hurt a lot: a child's book about death**

Doris Sanford; illustrations by Graci Evans. Multnomah Press: USA, 1986

**The very best of friends**

Margaret Nild and Julia Vivas. Margaret Hamilton: Sydney, 1989.

**How it feels when a parent dies**

Jill Krementz. Alfred A. Knopf: New York, 1991.

**Badgers parting gift**

Susan Varley. Ramdon Century: London, 1984.

**Goodbye Pappa**

Una Leavey &amp; Jennifer Eachus. Orchard Books: London, 1996.

**Help for the hard times – getting through loss**

Earl Hipp. Hazelden: Minnesota, 1995

**Beginnings and endings with lifetimes in between**

Bryan Mellonie and Robert Ingpen. Hill of Content: Melbourne, 1995

**Internet resources****American Cancer Society** – articles for children and parents[www.cancer.org](http://www.cancer.org)**The Captain Chemo Web Site**[www.royalmarsden.org/captchemo/index.asp](http://www.royalmarsden.org/captchemo/index.asp)**Mira's month** by The Blood and Marrow Information Network

USA 1994

[www.bmtnews.org](http://www.bmtnews.org) or[www.oncolink.upenn.edu/specialty/med\\_onc/bmt/mira.html](http://www.oncolink.upenn.edu/specialty/med_onc/bmt/mira.html)**Parent's page** by Nuala O'Leary LGSW[www.hopkinscancercenter.org/living/parents.cfm](http://www.hopkinscancercenter.org/living/parents.cfm)**Breast cancer: Common reactions of children and how to help** by

Jane Brazy and Mary Ircink, RN

<http://www2.medsch.wisc.edu/childrenshosp/childrens.html>**Patient information kids page**

Gynaecological Cancer Research Centre (University of Melbourne)

<http://128.250.188.72/gcrc/patinfo/kids.htm>page  
20**Information, support and research**

The Cancer Society of New Zealand offers information and support services to people with cancer and their families. Printed materials are available on specific cancers and treatment. Information for living with cancer is also available.

The Cancer Society is a major funder of cancer research in New Zealand. The aim of research is to determine the causes, prevention, and effective methods of treating various types of cancer.

The Society also undertakes health promotion through programmes such as those encouraging SunSmart behaviour and discouraging tobacco smoking.

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### **Central Districts Division**

PO Box 5096, Palmerston North  
Telephone: (06) 364-8989  
Covering Taranaki, Wanganui,  
Manawatu, Hawkes Bay and Gisborne

### **Wellington Division**

52 Riddiford Street, Wellington  
Telephone: (04) 389-8421  
Covering Marlborough, Nelson,  
Wairarapa and Wellington

### **Canterbury/West Coast Division**

PO Box 13450, Christchurch  
Telephone: (03) 379-5835

### **Otago/Southland Division**

PO Box 6258, Dunedin  
Telephone: (03) 477-7447

### **Cancer Information Service 0800 800 426**

[www.cancernz.org.nz](http://www.cancernz.org.nz)

### ***We would like your support***

*The Cancer Society receives no direct financial support from Government so funding comes only from donations, legacies and bequests.*

*You can make a donation by phoning 0900 31 111 or by contacting your local Cancer Society.*