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Cancer in the Family

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LIVING WITH CANCER

Cancer in the Family



Talking to your children





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Publications Statement

The Cancer Society's aim is to provide easy-to-understand and accurate information on cancer and living with cancer.

Our *Living with Cancer* and *Understanding Cancer* information booklets are reviewed every four years by cancer doctors, specialist nurses and other relevant health professionals to ensure the information is reliable, evidence-based and up-to-date. The booklets are also reviewed by consumers to ensure they meet the needs of people affected by cancer.

Other titles from the Cancer Society of New Zealand/Te Kāhui Matepukupuku o Aotearoa

Booklets

Advanced Cancer/Matepukupuku Maukaha
 Breast Cancer in Men: From one man to another
 Bowel Cancer/Matepukupuku Puku Haumuti
 Bowel Cancer and Bowel Function: Practical Advice
 Breast Cancer/Te Matepukupuku o ngā Ū
 Cancer Clinical Trials
 Complementary and Alternative Medicine
 Chemotherapy/ Hahau
 Eating Well/Kia Pai te Kai
 Emotions and Cancer
 Got Water?/He Wai?
 Lung Cancer/Mate Pukupuku Pūkahukahu
 Melanoma/Tonapuku
 Prostate Cancer/Matepukupuku Repeure
 Radiation Treatment/Haumanu Iraruke
 Secondary Breast Cancer/Matepukupuku Tuarua a Ū
 Sexuality and Cancer/ Hōkakatanga me te Matepukupuku
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Brochures and DL cards

Being Active When You Have Cancer
 Talking to a friend with cancer
 Being Breast Aware
 Bowel Cancer Awareness
 Gynaecological Cancers
 Thermography

Cancer in the Family: Talking to your children

Cancer touches the lives of many people. Every year in New Zealand, approximately, 25 percent of those diagnosed with cancer have children under 18 years old. When you are diagnosed with cancer, thoughts of your own wellbeing are quickly followed by thoughts or concerns for your children. Although this booklet has been written for parents, it is equally relevant for any family members, caregivers or kaiāwhina who are significant in the life of a child.

Children and teens can learn to cope with your diagnosis and the changes and challenges it will mean for your family. They will cope more effectively when they know what to expect. This starts with the important first step of sharing what you know. Experience shows children can cope with the situation and cope more effectively if they know what to expect. This booklet has been developed to support you in the difficult task of talking to your children about cancer. It has been divided into four parts:



Talking to your children about your cancer

The first section covers the why, who, when, how and what to tell a child. There are some examples of what a parent or caregiver might want to say. It includes typical responses of children according to different ages and developmental stages.

Coping with the changes

The second section includes information to help you to think about your children's thoughts and feelings. We suggest things to say and do, depending on the ages and developmental stages of your children. We cover some issues you may want to consider if you are not going to recover, and how you and other adults can help your children face the future. It includes comments on the value of keeping life as normal as possible.

Sharing experiences, good and bad

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

If you're not going to recover

The fourth section is about talking with your child(ren) about your prognosis, your plans for who will care for them, and ideas for providing them with 'heirlooms', such as photo albums and recordings.

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Talking to your children about your cancer

Why should children be told?

- A child has a right to know about anything important that affects their family/whānau, as cancer does.
- Children know something is wrong. If you try to protect them by saying nothing, they may have fears or ideas which are wrong or worse than the real situation.
- Not talking about cancer may suggest it is a subject too terrible to be discussed.
- 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/whānau matter.
- If your children know about your cancer diagnosis they will be less confused by the reactions of others.
- Younger children may notice things but misunderstand what they mean, which leads to confusion, 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 and support to you. You won't need to feel secretive and isolated in your own family/whānau.

- 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 take away their sadness, but we can share our thoughts and feelings, give them information about what is happening, and give them our support.

Who should tell the children?

- You should – if you think you can keep fairly good emotional control. It is alright to cry. Seeing you cry gives children permission to cry too. You will know in your heart if you can be the one to tell them.
- If you feel that you cannot tell your children yourself, perhaps a close relative, or friend, or your doctor or other appropriate professional could support you. Even if you cannot talk to them about it yourself at first, it will help if you can be there. Let them know why you find it difficult to talk about it and that you are still adjusting to the news yourself.

It may help to have another person there for support. Explain to the children that they too may like to choose someone special as their support person when they need to talk about cancer. Sometimes children do not tell their parents their worries or concerns as a way of protecting them or not adding to their stress. Encourage them to think of someone else that they trust and feel comfortable with and they can talk to.



When should I tell the children?

- After being diagnosed explain what is wrong.
- When you are being treated explain how the treatment is given, what the side effects might be, and whether things will be different at home.
- 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 health. It can be helpful to take your children to treatment. Talk to the staff first so they can spend time explaining things to your children.

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 as a family.
- You may want to practise what you will say and anticipate what questions your children might ask (see “Different ages and stages” later in this booklet).

- You will want to talk in a language each child understands – some children understand more when you draw pictures or use books, or both. See the list of books at the end of this booklet.
 - Assure them they will still be loved and cared for.
 - Listen to them.
 - Let them know it is okay to ask questions. Answer their questions simply. Ask them if they have understood your answers.

How much should I tell the children?

Children need to be given information they can understand in ‘bite-sized’ pieces.

- Tell them what has happened.
- Explain what will happen next.
- Leave them with thoughts and feelings of hope that even though you are upset now, there will be better times.
- It is okay to use the word ‘cancer’. You could explain that while cancer is a serious illness, the doctors have a plan for the best way to treat it.
- Timelines need to be linked to real life. For example, if you are going into hospital for two days, say it will be just like a weekend. If chemotherapy takes four hours to run, say it is as long as two movies.



- Correct any wrong ideas they may have.
- Be as clear as you can about how your cancer will affect your family.
- Let them know feelings as well as facts.

Some don'ts:

- Don't lie.
- Don't trouble them with frightening medical details, money worries (unless it will directly affect them), test results that are not in yet.
- 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". (Find out later if you can.)
- 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 alright for you to feel sad (or angry or happy or whatever)."

- "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 radiation treatment) 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."
- "Having cancer in our family makes all of us think and feel lots of different things. I know there are times when my cancer makes us frustrated or sad or worried. Remember that there are still lots of times when playing and having fun and going to school are important. I love to see you smiling and laughing but if you find you are feeling angry or sad, come and find me and we can work it out together."



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, re-organisation, 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 – reassure them you are coming home from hospital soon and that you think of them when you are apart. You may like to let them choose one of your favourite possessions to look after while you are away. A scarf, jersey or favourite pillow work well, as they hold your scent and may help to comfort young children. If they come to visit you, suggest they bring a favourite toy with them.

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

Children in this age group learn through repetition – you may have to explain many times. This is normal so try not to be frustrated. They are trying to understand your illness and how it will affect them.

Children in this age group have very little understanding of time. Try to explain time by relating it to things they may understand, such as “I’ll be taking medicine until Christmas”. Try to stick to your normal daily routines as much as possible.

Make information visual, such as a chart to count down the days you are having radiation treatment. Make a sign, for example, that shows a happy or tired face so they know how you are feeling.

Ages 6 to 12

Children between 6 and 12 may be very concerned about your health. It is important not to worry them with details that are very complicated but reassure them that you will keep them up-to-date.

For this age group, sticking to your normal routines is very important. It is a very good idea to inform your child’s teacher promptly about your cancer. Their understanding and support may be invaluable if there are any problems.

Let your children guide you as to how much information they want others, such as friends, to know. They may like to involve friends as a support system, or keep school and school friends as normal as possible.



Changes in eating, sleeping, schoolwork, behaviour and friendships may happen. Children, at any age, may start behaving like younger children. This may be their way of coping. With time, this should settle down. If problems continue, talk to a health professional.

Be aware that children may be getting information about cancer from various sources. Not all of it may be relevant to you. It may be helpful to check in with them from time to time to ask if they have any questions or need anything explained.

Source: Cancer Council NSW

For the parent

Children ages 8 to 12 can understand their parent's cancer diagnosis and will need more detailed information regarding what treatment their parent will be going through. They often deal with feelings of sadness, fear and confusion, and may become very clingy to a sick parent. Children may feel that as long as they are near, the parent will be okay. They can experience intense anxiety over a day at school or a slumber party at a friend's house. At this age, a child needs to discuss their feelings thoroughly and repeatedly. It may be difficult for a child to understand what they are feeling and parents should help interpret their actions. For example, you could say "I understand that going to school is difficult because you worry something might happen to me but it is important for you to go to school. I promise if anything happens, such as if I need to go to the hospital, I will make sure we call the school and let them know". When a child's feelings are validated

and talked about, the child will eventually have a greater understanding of his or her feelings.

Source: [www.http://kidskonnected.org/kids/default.html](http://kidskonnected.org/kids/default.html)

Teenagers (13 to 18 years)

Talk openly with your teen about resources and support that is available. Many teens access the internet and may find information that is not relevant for you and your cancer. Let them know that there are websites that have been recommended. Reassure them about your plan for treatment and how that will affect them.

Many teenagers have an especially hard time – adolescence is not an easy time in any case. Their thoughts and emotions are sometimes complicated and troublesome. They may find it hard to talk to you or show you how they feel. At times their behaviour may be difficult for everyone to deal with. When they are 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 help to reassure them that talking about their feelings and worries is a positive way of coping. If they are finding it hard to talk to you, encourage them to talk to someone close who can support them, such as a family/whānau member, friend, school or community counsellor.



Talk to them about how they may be of help. Reassure them that you still need them to be themselves, and to maintain their own interests. Your illness may mean that they are asked to take on more responsibility than they had before. This can be a positive experience if they feel their efforts are helpful and recognised. Difficulties can arise if they feel overburdened with responsibility and don't have time to do their 'own thing'. Teenagers need to be included and consulted as adults but will continue to need guidance, support and reassurance.

Children's reactions and needs at different ages

Children's understanding of illness and the implications of bad news varies depending on their age and family experiences. These charts give an overview of children's different needs, which can be helpful when working out what to say to children and how you might respond to lessen the impact of the news on them.

Newborns, infants and toddlers

Understanding of illness	Possible reactions	Suggested responses
They have little awareness of illness. Infants are aware of feelings that parents show, including anxiety	newborn and infants: unsettled, especially if weaned suddenly newborn and infants: may want to increase breastfeeds for emotional comfort	Provide consistent caretaking by maintaining baby's or toddler's schedule.

Newborns, infants and toddlers *continued*

Understanding of illness	Possible reactions	Suggested responses
They get upset when the presence of a physical and loving parent is missing. Toddlers may react to physical changes in their parent or relative or the presence of side effects (eg. vomiting)	fussy and cranky clingy change in sleeping or eating habits colic toddlers: tantrums, more negativity (saying 'no') return to thumb-sucking, bed-wetting, baby talk, etc.	Give plenty of physical contact (patting, hugging, holding, extra breastfeeds) to help them feel secure. Ask family members and friends to help with household tasks and care. Observe play for clues to their adjustment. Use relaxation tapes, music or baby massage. Express your feelings and fears with others.



Preschool and kindergarten 3-5 years

Understanding of illness	Possible reactions	Suggested responses
<p>They have a beginning level of understanding about illness</p> <p>Children may believe that they caused the illness, eg. by being naughty or thinking bad thoughts – this is called magical thinking.</p> <p>Children are egocentric and think everything is related to them.</p> <p>Children may think cancer is contagious.</p>	<p>thumb-sucking</p> <p>fear of the dark, monsters, animals, strangers and the unknown</p> <p>nightmares</p> <p>sleepwalking or sleep talking</p> <p>bedwetting</p> <p>stuttering or baby talk</p> <p>hyperactivity or apathy</p> <p>fear of separation from significant others (especially at bedtime and going to preschool)</p> <p>aggression (eg. hitting or biting)</p> <p>repeated questions about the same topic, even if it has been discussed several times</p>	<p>Provide brief and simple explanations about cancer. Repeat or paraphrase when necessary.</p> <p>Talk about the illness using picture books, dolls or stuffed animals.</p> <p>Read a story about nightmares or other problems.</p> <p>Assure them that they have not caused the illness by their behaviour or thoughts, nor will they catch cancer.</p> <p>Explain what children can expect; describe how schedules may change.</p> <p>Reassure them that they will be taken care of and will not be forgotten.</p> <p>Encourage them to have fun.</p> <p>Listen and be alert to their feelings, which they may express through speech and play.</p> <p>Continue usual discipline and limit setting.</p> <p>Let children get physical activity every day to use up excess energy, get rid of anxiety and to provide a positive outlet for any aggression.</p>

Primary school 6-12 years

Understanding of illness	Possible reactions	Suggested responses
<p>Able to understand more complex explanations of cancer and basic information about cancer cells.</p> <p>They may feel responsible for causing illness because of bad behaviour.</p> <p>Younger children may be starting to understand that people, including parents, can die. Older children tend to understand the finality of death and its impact. If a child has been exposed to illness or death at a young age, they may have a more mature understanding of dying.</p>	<p>irritable</p> <p>sadness, crying</p> <p>physical complaints: headaches, stomach-aches</p> <p>sudden worry about health of the well parent</p> <p>separation anxiety when going to school or away to camp</p> <p>regressive behaviour</p> <p>hostile reactions like yelling or fighting, including towards the sick parent</p> <p>poor concentration, daydreaming, lack of attention</p> <p>poor marks</p>	<p>Listen and be alert to their feelings, which they may express through speech or play.</p> <p>Use books to explain the illness, treatment and potential outcomes.</p> <p>Assure them that they did not cause the illness by their behaviours or thoughts.</p> <p>Reassure them about the care and schedules.</p> <p>Tell them that their other parent and other relatives are healthy.</p> <p>Let them know how you care about their feelings.</p>

Primary school 6-12 years *continued*

Understanding of illness	Possible reactions	Suggested responses
	<p>withdrawal from family and friends</p> <p>difficulty adapting to changes</p> <p>fear of performance, punishment or new situations</p> <p>sensitivity to shame and embarrassment</p> <p>trying to be extra good, with the risk that their distress and anxiety is not identified by parents – this is more common in girls.</p>	<p>Address the issue of dying even if children do not bring up the topic.</p> <p>See also ideas for younger children.</p>

Secondary school 13-18 years

Understanding of illness	Possible reactions	Suggested responses
<p>They are capable of abstract thinking they can think about things they have not experienced themselves.</p> <p>They are starting to think more like adults.</p> <p>They are able to understand that people are fragile.</p> <p>They are able to understand complex relationships between events.</p> <p>They are able to understand causes and effects: relating to symptoms and illness or between actions and outcomes.</p> <p>They are more likely to deny fear and worry in order to avoid discussion.</p>	<p>want to be more independent and treated like adults</p> <p>anger and rebellion</p> <p>critical of how adults react to or handle the situation</p> <p>depression or anxiety</p> <p>worry about being different</p> <p>poor judgement and risk-taking behaviour (eg. alcohol abuse, smoking, staying out late, unsafe sex)</p> <p>withdrawal</p> <p>apathy</p> <p>physical symptoms from stress (eg. stomach-aches, headaches)</p>	<p>Encourage them to talk about their feelings, but realise they may find it easier to confide in friends, teachers or other trusted people.</p> <p>Provide plenty of physical and verbal expressions of love.</p> <p>Talk about role changes in the family.</p> <p>Provide privacy as needed.</p> <p>Encourage them to maintain activities and friendships.</p> <p>Set appropriate limits.</p> <p>If there are problems, provide opportunities for counselling.</p>

Secondary school 13-18 years *continued*

Understanding of illness	Possible reactions	Suggested responses
	<p>more likely to turn feelings inward (so adults are less likely to see reactions)</p> <p>regression: some lapse into previous behaviours such as watching children's TV shows or being insecure and dependent on parents.</p>	<p>Don't rely on them to take on too many responsibilities.</p> <p>Provide resources for learning more about cancer and getting support.</p> <p>Make agreements that you don't always want to talk about cancer: you still want you and your kids to talk about homework, sport, friends, boyfriends/girlfriends, their part-time job etc.</p>

Reprinted with permission from Cancer in the Family: helping children cope with a parent's illness, American Cancer Society 2001

Here are some ways you can encourage some expression and discussion in children or teens:

- encourage physical activity and sport
- run, jump, play, dance, walk to get stored-up energy out
- talk about what's happening:
 - with young children, using a doll house, puppets, stuffed animals or a phone
 - with teens, maybe while driving or taking a walk somewhere. It can be helpful doing something as you talk.
- drawing, painting
- clay, play dough
- take photos, make videos
- music – write songs, play songs, listen to music or dance to music
- storytelling and reading – see the booklist at the end of this booklet
- writing – stories, poems, a journal, or a letter.



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. It is normal for kids to think mostly of themselves. Even when you feel grotty, they may be more concerned with how it affects them, that your cancer is not fair for them, or about the next thing they want to do. This is frustrating, but totally normal. Often as children get older they recognize that it is difficult and unfair for you as well. They may feel upset or guilty about the moments that they have focused on themselves. Be as open about it as you can. This is a difficult time for everyone.

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. Finding out as much as you can about your cancer may make things less scary.

Changes

Everyone in your home will be affected by your cancer, even if they don't all express their thoughts. 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/whānau'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/whānau member may have to take over some of the things you usually do. Ask for support from others if necessary, especially if you have side effects from treatment that is worrying your children. It is best, if possible, to have the same person helping, especially when there are children who need consistent care and support.

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 your child won't be, and he or she will accept the changes easily. Curiosity may mean they ask some matter-of-fact questions about what they observe.

Your children may not want people to know things have changed in your home. Let them know you are willing to talk to their friends if they want you to, or to help them figure out/practise how they would like to tell their friends themselves. Talk about some of the questions they might ask and what the answers could be. It may be helpful to talk to your children's teachers to let them know how things have changed for you.

Try to be relaxed if changes need to be made, and involve children as much as you can in new plans. Children respond differently and have different needs at different ages (see the section 'Different ages and stages').



If you and your children are having ongoing problems, let your GP and the hospital know. Don't hesitate to ask for professional counselling. It may be possible for the whole family/whānau 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. The Cancer Society has a service called Cancer Connect where you can be connected with someone who has had a similar experience. Call the Cancer Information Helpline for more information on **0800 CANCER (226 237)**. Ask your local Cancer Society if there are any books that may be helpful. Some recommended books are listed at the back of this booklet.

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. (For teenagers: let them know the usual rules apply, such as curfew, expectations about behaviour, rules about drugs, alcohol, unsafe sex...)

If you notice a consistent change in behaviour you may like to plan on spending some more one-on-one time with your child. Suggest that if it is hard to ask for your attention, they could use a sign or secret code that you have thought up together. They can, for example, put a magnet on the fridge next to a picture of the two of you when they need a hug.

Children's thoughts and feelings

If you never show how you feel or talk about your thoughts, 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 thoughts and feelings instead of accepting them as normal.

You will have many feelings about your diagnosis. Don't be afraid to express them. If you are sad, cry. If the children are sad you can cry with them – it may help to ease the tensions. It is important to talk to them about how you think and feel and what you do to cope. Ask them to think of a time when they were angry or sad. What did they do to make themselves feel better? Would that work now? What else might you do?

Some children may:

- feel sorry for themselves when the person who cares for them is ill, and then feel guilty because they think they should feel sorry for the parent or caregiver.
- try to make up for those guilt feelings by being super good and setting impossibly high standards for themselves.



- cling to you too much – afraid something will happen if they are not there.
- withdraw from you, unconsciously trying to become more independent in case something else happens to you.
- resent the fact that they need to help you when the opposite was true before.
- laugh and behave badly to cover up their real feelings or their lack of understanding (especially in strange situations).
- 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.
- be afraid they'll get cancer too, or that others they love might.

Let your children know that you understand and accept them. Talk to them about how they are thinking and feeling and if you notice changes in their normal behaviour. Remember that this may be their way of coping and that it is okay as long as it does not stop them participating in their usual activities, such as school. If you have concerns don't be afraid to ask for support. There are many other families who will have struggled with the same issues.

Sharing experiences, good and bad

Time with your 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, or write a story about your family/whānau and share it with them. Have play dough and other creative materials to use to work out some frustrations that you and the children share. Plan for laughter, such as watching a funny DVD together. Laughter is good medicine for all of you.

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, for example, use of the cafe or outdoor areas.
- stay in touch with phone calls, emails, texts or little notes sent back and forth.
- share recorded messages.
- exchange pictures or photographs.
- exchange presents. You can pack small gifts to give children when they visit you; select things that they can do on their own or with you whilst they are visiting.



- Children may be interested in all the mechanics of a hospital. Explain how the bed works, the call button, and all the different people who are there to help you.
- Explain procedures if your child shows interest or concern.

Remind children that all of the tubes, bells and whistles have a purpose. Children may be overwhelmed by them. Tell your children beforehand that it is okay to get up on the bed, and give you a gentle cuddle.

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.
- Read a book together about the body. You could point out where your cancer is and what is happening to you.
- Role play with younger children. Act out what is happening to you by using a doll. Try not to use any special dolls or animals that they use as a comfort toy unless they request it. Use other dolls for other members of your family/whānau. Children often express what they are really feeling in their play. Listen.
- Share meaningful stories and songs with your children.

- Make up positive messages to help all of you. Make posters, mobiles or badges using the positive message for inspiration.
- Teenagers may find some websites helpful (see the website list at the end of this booklet).

Benefits of sharing

You may be spending more time with your 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/whānau may discover reserves of love and inner strength that will enhance the rest of your life together.



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/whānau 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 your children. If you find you can't talk about it, there are others who may be able to help. These may include a trusted family/whānau member, a friend, doctor, nurse or religious or spiritual person who knows your family/whānau and your values.

Younger children can have difficulty understanding the concept of death. In some cases professional help may assist. Child psychologists or psychotherapists trained in a variety of therapies can help any age group.

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".

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.

Children learn about solitude, intimacy and companionship by being quietly in someone else's company. You can be together without necessarily needing to talk, for example, when you are reading, drawing, and making things.

Your children will probably ask questions, such as:

What about me?

- What will happen to me?
- Am I going to die too?
- Will others 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. What is most important is that your child feels able to voice their concerns, questions, and their thoughts and feelings are taken seriously.

Children may ask questions over and over to try to understand what's going on. Try and give consistent answers and information. Be aware that children's level of understanding may change during your illness.

Here are some things you could say in answer to:

“What will happen to me?”

“Daddy/Mummy/Granny, for example, will still be here and will look after you. Daddy will take you to school and Auntie will collect you after school and you will stay with her until Daddy comes home and collects you. Uncle will take you to swimming/football.”

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 is healthy at present and there is no reason for you to think that they will die soon.”

“What about you?”

You may feel comfortable talking about your death with your 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 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.”

Talking about dying

“Although Mummy is dying, the family/whānau 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/whānau 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”.



“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.”

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.”

Here’s an example of how death and a funeral can be explained to a child.

“When someone dies their body is no more use to them. It cannot feel pain, happiness, hunger or sadness. A dead body has stopped working forever. 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. Their coffin is 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 will talk about Mummy. Is there something that makes you think of Mum – a special song or story that you would like to share at the funeral?”

Feeling a part of this ceremony can give children a sense of belonging.

Tangihanga

Tangihanga is one of the most important cultural rituals of Māori. While it is an emotional time for all, it also unites members of the whānau, hapū and iwi who are affected by the ‘mighty hand of death – te ringa kaha o aituā. The formalities begin with the karanga – the call of welcome by selected women – onto the marae. Women from the visiting group of mourners respond in kind. They are directed to seating while close members of the deceased’s family may approach and sit beside the body. Formal speeches by the local male leaders begin and are replied to by males from the visiting group.

Speeches on the marae ātea are usually in Māori. However, if the body is held inside the meeting house, opportunities are given for women and even young adults to pay their respects in English.



Children are an integral part of the mourning and farewelling ceremonies, often being seated beside the open coffin. These speech formalities are completed by the hongī, the pressing of noses, between visitors and local people.

Young people are often seen working in the kitchen, providing food and drink as part of the process of removing the tapu from the visitors. This is called whakanoa. Tangihanga generally last for three days but may be prolonged for up to a week. Nowadays, tangihanga are also held in family homes, community halls and urban marae.

After the burial, the ritual of 'takahi whare' occurs to remove any lingering spirits, followed by a formal hākari.

The ritual of 'kawē mate' – taking the spirit of the deceased to related marae – takes place some time after the burial.

After a year, the unveiling of a headstone – te hura kōhatu – takes place to commemorate the passing of a loved one.

Lee Smith

Afterwards

You can help children face life afterwards by preparing them for the future without you. A letter or DVD from you to be read/viewed later can be very positive.

You can make a photo album or scrapbook with photos recording the child/children's babyhood and childhood, with messages about how you felt about your child at the time the photo was taken. You could select a special treasure that is significant to each of your children individually – this does not have to be a bit of jewellery or a family heirloom – something that they associate with a memory of you. Leave a story with it. You can, for example, leave their baby blanket, the shells you collected together at the beach, the first drawing they did for you. It doesn't have to be fancy or expensive, but these things show your children that you valued and treasured them and your times together.

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

As a 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. For more information, contact your local Cancer Society or call **0800 CANCER (266 237)**. The Cancer Society has a booklet titled *Advanced Cancer: A guide for people with advanced cancer* that you may like read.

“It's very important to me to make sure you will be safe and looked after, so I've talked to mum/dad/grandpa about what is going to happen. We will talk to you about it as well.”



Recommended reading list

Here are some suggestions for reading. Many will be available to borrow from your local Cancer Society's lending library. Your local library may have others you may find helpful.

Books

Books for parents

Heiney, Sue P et al. (2001). *Cancer in the Family – helping children cope with a parent's illness*. USA: American Cancer Society.

Kohlenburg, Sherry. (1993). *Sammy's Mommy has Cancer*. Washington: Magination Press.

McCue, Kathleen and Bonn, Ron. (1996). *How to Help Children Through a Parent's Serious Illness*. USA: Universal Press Syndicate.

Rauch, Paula K and Muriel, Anna C. (2005). *Raising an Emotionally Healthy Child When a Parent is Sick*. USA: McGraw-Hill.

Russell, Neil. (2001). *Can I Still Kiss You? Answering your children's questions about cancer*. Florida: Health Communications Inc.

Schlessel Harpham, Wendy. (2004) *When a Parent has Cancer – a guide to caring for your children*. USA: HarperCollins.

Van Dernoot, Peter. (2006) *Helping your Children Cope with your Cancer : A guide for parents and families*. USA: Hatherleigh Press.

Books for younger children

Buckley, Colleen. (2007). *Grandma Kathy has Cancer*. Indianapolis: Dog Ear Publishing.

Carney, Karen. (1999) *What is Cancer Anyway?* USA: Dragonfly Press.

Garden-Bachop, Sue. (2006). *Who Will Tuck Me In?* Wellington: Sue Garden-Bachop.

Blunt, Lucy. (2009). *My Mum's got Cancer*. Australia: Jane Curry Publishing.

McVicker, Ellen. (2006). *Butterfly Kisses and Wishes on Wings*. www.butterflykissesbook.com

Sachedina, Shenin. (2007) *Metu and Lee Learn About Breast Cancer*. USA: Dr. Shenin Sachedina Medical Educational Products.

Silver, Alex, Emily and Anna Rose. (2007). *Our Dad is Getting Better*. American Cancer Society.

Silver, Alex, Emily and Anna Rose. (2007). *Our Mum is Getting Better*. USA: McGraw-Hill.

Skylight. (2000) *When something has happened*. NZ :Skylight (reprinted 2010).

Varley, S. (1992). *Badger's Parting Gifts*. UK: Picture Lions Collins.

Boritzer, Etan. (2000) *What is Death?* Los Angeles: Veronica Lane Books.



Books for older children

Cancer Council Queensland. *What About Me?*
www.cancerqld.org.au/f/OrderBrochures/Public

Couldrick Anne (1991) *When Your Mum or Dad has Cancer*.
 UK: Sobell Publications.

Hyman Fead, Beverley and Hamermesh, Tessa Mae. (2009).
 Nana, *What's Cancer?* USA: American Cancer Society.

Krementz, J. (2001) *How It Feels When A Parent Dies*.
 New York: Alfred A Knopf.

Skylight (2009) *The journey through: Ideas for getting through tough times*. NZ: Skylight.

Skylight (2010) "Getting Stronger" (a board game).
 NZ: Skylight.

Skylight (2001) *When tough stuff happens*. NZ: Skylight.

Speltz, Ann. (2003) *The Year My Mother Was Bald*. United States: Magination Press.

Stokes, Julie A. (2000). *The Secret C – straight talking about cancer*. UK: Winston's Wish.

Websites (suitable for teenagers)

Skylight
www.skylight.org.nz

CanTeen (NZ)
www.canteen.org.nz

My Parents Cancer
www.myparentscancer.com.au

Rip Rap
www.riprap.org.uk

Now What
www.nowwhat.org.au

A National Cancer Institute online booklet
When a Parent has Cancer: A guide for teens
www.cancer.gov/cancertopics/coping/familyfriends

Websites for parents

Bear Essentials
www.bear-essentials.org
 Includes suggestions for kids' activities to aid discussion.

Cancer Council NSW online booklet
When a parent has cancer: how to talk to your kids?
www.cancercouncil.com.au

Websites for the family

Kids Connected
www.kidsconnected.org

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Notes

You may wish to use this space to write down any questions you want to ask your doctor, nurses or health providers at your next appointment.



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Notes

Cancer Society of New Zealand Inc. Te Kāhui Matepukupuku o Aotearoa

Cancer Society of New Zealand Inc.

www.cancernz.org.nz

National Office

PO Box 12700, Wellington 6144

Telephone: (04) 494-7270

Auckland Division

PO Box 1724, Auckland 1140

Telephone: (09) 308-0160

Covering: Northland

Waikato/Bay of Plenty Division

PO Box 134, Hamilton 3240

Telephone: (07) 838-2027

Covering: Tauranga, Rotorua, Taupo,

Thames and Waikato

Central Districts Division

PO Box 5096, Palmerston North 4441

Telephone: (06) 364-8989

Covering: Taranaki, Wanganui, Manawatu,

Hawke's Bay and Gisborne/East Coast



Wellington Division

52-62 Riddiford Street, Wellington 6021
Telephone: (04) 389-8421
Covering: Marlborough, Nelson, Wairarapa and Wellington

Canterbury/West Coast Division

PO Box 13450, Christchurch 8141
Telephone: (03) 379-5835
Covering: South Canterbury, West Coast, Ashburton

Otago/Southland Division

PO Box 6258, Dunedin 9059
Telephone: (03) 477-7447

Feedback

Cancer in the Family: Talking to your children

We would like to read what you thought of this booklet: whether you found it helpful or not. If you would like to give us your feedback please fill out this questionnaire, cut it out and send it to the Information Manager at the address at the bottom of the following page.

1. Did you find this booklet helpful?

Yes No

Please give reason(s) for your answer.

2. Did you find the booklet easy to understand?

Yes No

Please give reason(s) for your answer.

3. Did you have any questions not answered in the booklet?

Yes No

If yes, what were they?



4. What did you like the most about the booklet?

5. What did you like the least about the booklet?

6. Any other comments?

Personal information (optional)

Are you a person with cancer, or a friend/relative/whānau?

Gender: Female Male Age _____

Ethnicity (please specify): _____

Date: _____

Thank you for helping us review this booklet.

The Editorial Team will record your feedback when it arrives, and consider it when this booklet is reviewed for its next edition.

Please return to: The Information Manager, Cancer Society of New Zealand, PO Box 12700, Wellington 6144.

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.

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, being physically active and eating well and discouraging smoking.

We would appreciate your support

Many Cancer Society services would not be possible without the generous support of many New Zealanders. You can make a donation by phoning 0900 331 111, through our website at www.cancernz.org.nz or by contacting your local Cancer Society.

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Information Manager

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Cancer affects New Zealand from all walks of life, and all regions of our beautiful country. This cover photo of the beach and family in Eastbourne, Wellington was taken by Mark Coote.

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www.cancernz.org.nz

ANY CANCER, ANY QUESTION

0800 CANCER (226 237)

Cancer Information Helpline

