

SUPPORTING A CHILD THROUGH A LOVED ONE'S CANCER DIAGNOSIS

An information sheet for patients, families and whānau



A cancer diagnosis can affect the entire family in different ways. Helping children to understand cancer and how this will impact them will help them to cope with the changes and challenges.

Naturally, talking to children about a sensitive topic like this can be difficult.

This factsheet contains a few tips to help support you. But remember, you are the expert when it comes to your own child and the support they need.

Have honest conversations

People sometimes feel that by not telling children about a cancer diagnosis they are protecting them, but children often sense that something serious is affecting the family. They can pick up on unusual comings and goings, hushed conversations or a different atmosphere about the house. When they don't know what's going on they can misunderstand the situation or can feel vulnerable and isolated. Having open, honest conversations together is the best way to avoid confusion and help their understanding. When children understand more about the situation it can help reduce their anxiety.

Be prepared

It's important that you have all the information you need to understand things yourself and for you to cope with your own feelings. It may help for you to talk with your medical team or your Support Services Coordinator from Leukaemia & Blood Cancer New Zealand (LBC). You might find it helpful to rehearse what you want to say to children with a partner, relative or close friend.

Books for children can help as bridges for conversations and understanding

There are many age-specific resources available to support children affected by cancer.

Age-appropriate books can be a great way for children to learn more about cancer and about how they are feeling. Ask your LBC Support Services Coordinator if you would like to receive copies of these books.

When and how to speak to your child

- Speak to children as early as possible, before they start to pick up on the kind of changes that might cause them to worry.
- Call the cancer by the name 'cancer' and give a simple explanation of what it is. This will encourage a child to talk openly about cancer.
- Use words and phrases a child will understand.
- Give small chunks of key information and avoid over-explaining. The younger a child is, the more 'bite-sized' the chunks of information need to be.
- Find out what they know, or think they know, and correct any misunderstandings.
- Be as specific as you can. Children are more prone to worry when things aren't clear.
- Ask them if there's anything else they want to know.

A child's understanding is a process that unfolds over time. Children tend to 'dip in and out' of discussions. Often people prepare for a lengthy conversation and wonder if they did something wrong if the child changes the subject after only a couple of questions. Be reassured that if this happens, it isn't that you have done or said something wrong, it's more likely that is all your child wants/needs to know right now.

The important thing is to emphasise that they can ask you questions at any time and to keep lines of communication open.



Their reactions

It's not uncommon for children to express all kinds of emotions soon after hearing bad news. Be ready for however they need to react. For example, it could be with silence, or with anger, or with endless questions. Every child will be different.

Tears are normal – theirs or yours, or both. Reassure them that tears are just a way we express sadness or shock when difficult things happen.

Some children may need extra attention and time with you, but they might also need some time by themselves to think about it all, or talk with others about the diagnosis.

Children can ask questions that you weren't prepared for. These might come quite some time after they first learn about the diagnosis. It's fine to say that you don't know if you don't have the answers to their questions. Tell them you'll try to find out and come back to them.

What children need to know to understand a diagnosis

How their lives and routines are likely to be affected

It's important to try to keep family life as normal and stable as possible. Continue as normal with usual

discipline and setting boundaries, but be aware that some flexibility may be appropriate at times. Children will also need to be prepared that there may be some changes in their day-to-day routine.

Encourage children to maintain their regular activities and friendships. Keep them in the loop by telling them what's happening – for example let them know who will be picking them up from school, making dinner and putting them to bed. This can give them security, especially during the early days of diagnosis and treatment when life can be unsettled. Children need to be reassured that there will always be someone to take care of them. For younger children this practical information will be their main concern, but older children may be more occupied with the emotional impact.

It may be helpful to talk to older children about ways that they could help and contribute. This can be a positive experience if they feel their efforts are helpful and recognised, but make sure they are given responsibilities that are appropriate for their age.

Who is in their 'support team'

It can be useful to help children identify who is in their 'support team' of people that they can talk to. Encourage them to talk to others. Children can be quite protective of their parents and might not want to ask questions they think will upset them. Their



'team' might include older siblings, aunts, uncles, grandparents, friends' parents or teachers who they can talk to if they need to. It helps for children to talk about normal feelings.

Nothing they, or anyone else, did or thought caused the cancer

Children need reassurance that cancer is not their fault. They might think the cancer is a result of bad behaviour or because they were once angry with the person who has been diagnosed. It is not uncommon for children to feel that they are to blame, and can sometimes feel guilty. Reassure them more than once that it's not anyone's fault. They can always ask you questions and talk to you about how they feel. Children need to know you'll listen to their worries and try to help them cope.

Cancer isn't like a cold and you can't catch it – it's okay to sit close and give lots of cuddles.

Explaining treatment

Knowing about treatment and any potential side effects can help children prepare for what to expect. This can also help reduce their anxiety and worry. Children usually cope and adjust well if they're told in advance about any changes in appearance due to treatment. Some children may worry that the cancer is getting worse if they see

someone unwell due to treatment, so it's important that they understand that side effects don't mean deterioration in health. Explain that not everyone gets the same side effects. Tell your children that side effects will get better once treatment has finished, but that it might take some time.

Some suggestions for talking about chemotherapy

- Chemotherapy can make you feel sick but you'll take medicine to help.
- Chemotherapy can make you feel very tired so you'll need to get lots of rest or sleep.
- Germs don't cause cancer but chemotherapy can make it easier for you to catch a cold or get an infection.
- Your hair may fall out and if it does you'll be able to wear a wig or hat and your hair will grow back again when the chemotherapy finishes.

LBC Sticker Diary and Journal

LBC have a sticker diary and journal which you can encourage your children to use to record when you go to hospital and when you have your treatment. This can help them feel involved in your treatment. They can also journal any questions they have for you or write down or draw about anything they are worried about. This can help when you are talking to your child about how they are feeling.

