



When your child has cancer:

*Caring for  
your wellbeing*



The Child Cancer Foundation has teamed up with Senior Clinical Psychologists from the Massey University Cancer Psychology Service to put together this booklet about emotional reactions to cancer, which includes a "Wellness Check-In" for caregivers to talk about with their Family Support Coordinator (FSC).



Mason and his Dad

© (2019) Dr Kirsty Ross, Senior Clinical Psychologist and Senior Lecturer, Massey University, Palmerston North; Child Cancer Foundation of New Zealand.

# About this booklet

**This booklet is designed to give you some information about your emotions surrounding your child's cancer, as well as ideas for enhancing your wellbeing.**

Hearing your child has cancer is something no parent/caregiver wants to experience. Having a strong emotional response is understandable. Many people describe a reaction they say feels like grief, as they start to come to terms with their child's diagnosis and what it means.

Disbelief, denial, anger, anxiety, sadness and numbness are all common emotional reactions. People can experience different emotions at different times, including within their own whānau.

It is important that you keep in mind that your emotions are normal; no emotion is 'bad' or 'wrong'. It is also important to know that you are not alone, and you do not have to try to manage on your own.

As with other difficult times, people may already have ways to manage stress

and good supports in place to help them do so. Talking about how you are doing and how you are coping can help identify what you need to help you take care of yourself and your whānau during this difficult time.

The goal is to support your wellbeing as much as possible during the cancer journey. Getting the right help and support early will help you, your child and your family/whānau.

# Emotional responses following a child cancer diagnosis

**During the initial shock of diagnosis and starting treatment, families/ whānau sometimes feel like they are in survival mode, needing to deal with a new day-to-day reality.**

In addition to regular parenting, there are all the extra tasks involved in your child's medical care to manage, as well as providing information and updates to others, such as teachers, other family/ whānau and people in your community.

Many people may want to help at this time. Thinking of practical ways you can be supported is a good way to enhance your wellbeing, as well as giving people a sense of supporting you. Examples might be mowing lawns or doing household chores, bringing meals, doing grocery shopping for you, picking up siblings from school, and looking after other children when you need to be with your unwell child.

*"Our whole family were in disbelief. You're just running on adrenaline. You don't realise how terrifying it is and there are so many firsts – the first general anaesthetic, first blood transfusion, first dose of chemotherapy – it's a daunting experience," says Lara. "I didn't know life can go on. But then it starts to become normal, and it shouldn't."*

Some of the known emotional effects of hearing your child has cancer can include:

- high levels of distress and stress
- anxiety/worry and fear
- feeling that all you can think about is cancer
- sadness
- anger
- feeling no-one else understands, including your partner at times

These emotions can affect your sleep, and levels of fatigue/tiredness. They can lead to feeling tense, on edge and even experiencing physical pain and changes in appetite. Being able to un-wind your body is helpful for being able to deal with the physical impact of the cancer experience. Engaging in physical activity, relaxation strategies, and mindfulness are all helpful ways to keep your body well and strong.



What can be helpful in these early days is information from your health professionals and treatment team. Also, practical suggestions around managing aspects of treatment – such as how to help your child get through procedures like blood tests, and how to manage when they are on steroids. As the initial shock settles, other coping strategies covered in the booklet may be useful.

- Social support is really important. In addition to practical forms of help from friends and loved ones, It can be helpful to talk things through, take a break and do something non health-related, express your feelings with people you know and trust.

- Let people know what is going on and what you need. This is important for ensuring you get the support you need, when you need it. Sometimes people are reluctant to ask questions out of fear of upsetting you; they will take their lead from you as to when (and how) you want to talk about what you, your child and your family/whānau are going through.

It can sometimes feel as though these big emotions are affecting your relationship with your partner, your other children, colleagues, friends and other family members – and even your relationship with your child's medical professionals. These feelings can last a long time. For some people, the emotional impact of a cancer diagnosis can be delayed as they focus on their child's needs first.

*"They just wanted to know everything and asked so many questions. The challenge is that even for you at the time, you don't fully understand what it is. You get this massive folder when you have a diagnosis from the oncologist. I think I read that 10 times on the first day and it still felt like I didn't know what was going on. So when the kids were asking, we didn't know what to say."*

Josie's mum, Jacine.



Josie and her  
Mum and Dad

## You and your family/whānau

Cancer is a diagnosis that affects the whole family/whānau; the impact of childhood and adolescent cancer is not limited to the young people themselves; all those who love and care for the child are also affected. Your FSC will be able to direct you towards support available for different members of your family/whānau.

*"Knowing there is always someone to talk to, ask for help and especially the events that are organised that put you in contact with other families as well. The support is family wide, especially with siblings."*  
Nixon's Mum, Justine



Nixon and his  
Mum and Dad

## Siblings

Siblings/other people who are close to the young person also experience distress. Siblings may also experience problems with managing their emotional reactions to the cancer, if they do not have the opportunity to talk about their feelings and get the support they

need. **CanTeen NZ** has excellent resources on their website - [canteen.org.nz](http://canteen.org.nz) - for teenagers dealing with the distress arising from cancer. Your FSC can connect you to someone who can provide support and advice.



Riley and  
his siblings

## Caregivers

Many NZ families/whānau have to travel for treatment. Parents/couples often find themselves having to divide roles, and even the family. One parent often travels with the child to the treatment centre in Auckland or Christchurch, while the other partner/parent stays with the other children in the family.

Talking about how to work together as the main caregivers is important so you can manage the practical and emotional demands of cancer.

People often have different ways of coping. Being able to understand how other caregivers are managing, and being able to talk about things that help you cope, can reduce misunderstandings and increase the chances of doing what works for you all. This can help you feel more connected as caregivers.



*"We have a tradition of holding a family meeting every week – it even has its own theme tune.*

*We talk about the great things that have happened in the past week and celebrate successes together."* Lara.



Sydnee and her Mum



## Working together as a family/whānau

Consistency between parents/ caregivers is important for the child with cancer, and for their siblings. Sameness and routine can be reassuring and create a feeling for children that some things remain the same and are predictable even in the middle of a really difficult situation. Believe it or not, for children it can be comforting to know that they still have to do their chores! However, being flexible when you need to be is also okay;

a balance between doing things the same way, and doing things differently when you need to, is good. To help decide when things need to be different, being able to talk things through as a family/ whānau helps. 'Tag-teaming' when possible can also create opportunities for one-on-one time with other children to give them time to share with you what's happening in their world.



Arsenah and her  
family/whānau

# Communication needs connection: Ways to increase connection

## Connection leads to better communication.

You can improve your feeling of connection to your partner by:

- **Building companionship.** Share experiences, interests and concerns with your partner. Show affection and appreciation. Spend time together doing everyday activities – reading the paper, listening to music, watching TV, or doing laundry. Make small talk. Even making a grocery list together can be a way of sharing space and time, and can become a way of showing love—for instance, when you add your partner's favourite cookies to the list without being asked.
- **Sharing intimacy.** Intimacy is not only a sexual connection. Intimacy is created by having moments of feeling close and attached to your partner. It means being able to comfort and be comforted, and to be open and honest. An act of intimacy can be as simple as bringing your partner a cup of tea because you can tell they are tired, holding hands on the couch watching television or smiling at one another across a room.

## Enhancing communication

**Listening** is a key part of effective communication. A good listener can encourage their partner to talk openly and honestly. Knowing that you are being heard leads to a feeling of connection. One way to improve your listening skills is to use a technique called "active listening." This is a form of listening in which you acknowledge not only that you are listening—as with a nod of the head or saying "uh-huh"—but also that you understand what is being said.

Understanding can be communicated with a smile, a word or a phrase that captures what they're saying, or even with a simple "I understand"—if you really do understand. If you disagree with what is being said, or how the other person dealt with a situation, wait until they have finished talking before you disagree with their point of view.

### Tips for good listening include:

- listen to your partner. Put aside your own thoughts for the time being and try to understand their intentions, feelings, needs and wants (this is called empathy)
- keep comfortable eye contact (that fits with your culture)
- lean towards the other person and make gestures to show interest and concern
- sit or stand on the same level to avoid looking up to or down on the other person
- avoid distracting gestures such as fidgeting with a pen, glancing at your mobile, or tapping your feet or fingers
- let the other person speak without interruption
- show genuine attention and interest
- check your understanding; ask questions, and don't assume that you know the answers.



### Talking. When you talk to your partner, try to:

- set aside time to talk without interruption from other people or distractions like phones, computers or television
- think about what you want to say and make your message clear, so that your partner hears it accurately and understands what you mean
- talk about what is happening now and how it affects you; what you need; try not to bring up past events and issues
- accept responsibility for your own feelings
- be aware of your tone of voice
- negotiate and remember that you don't have to be right all the time. If the issue you are having is not that important, try to let the issue go, or agree to disagree.
- remember to also share positive feelings with your partner, such as what you appreciate and admire about them, and how important they are to you

### If conflict arises

During times of conflict, it is important to remember that using the silent treatment will not resolve anything! Keeping communication going is important.

- Try not to jump to conclusions and react based on assumptions – express that you are struggling/hurt/upset and find out the pieces of information you are missing.

- Discuss what has actually happened and try to understand your partner's actions and feelings – even if you disagree with them or feel differently.
- Try not to judge – the goal is to understand each other, and work together, rather than 'win'.
- Be prepared to take time out if you are feeling really upset about something. It might be better to calm down before you address the issue – but let your partner know that this is something that is important to talk about once you are both calm and ready to do so.
- Address important issues as they come up, rather than have them build up and add to each other. If this happens, you might react strongly to something based on unresolved issues, rather than the problem at hand. Then your partner might wonder why you are reacting so strongly to the current issue and feel that you are overreacting; this will make you feel unheard and misunderstood, and might lead to more resentment, distress and disconnection.



### A template for expressing how you feel is:

When \_\_\_\_\_ I feel \_\_\_\_\_  
because \_\_\_\_\_. What I need  
in the future is \_\_\_\_\_

**Example:** *"When [describe the situation or behaviours that are a problem for you], I feel [try to name your emotions accurately – angry, sad, worried, frustrated, happy – remember to communicate the good stuff too!], because [if you can explain why those behaviours/situations lead to those feelings for you, which might include past experiences you have had that your partner is unaware of]. What I need is [any changes in behaviour you need from your partner, or anything else you might need, such as practical or emotional support]."*

### Remember:

- No matter how well you know and love each other, you can't read your partner's mind (and they can't read yours).
- Clear communication helps to avoid misunderstandings that might cause hurt, anger, resentment or confusion.
- People have different communication needs and styles. It is good to talk about, and understand, how you talk and agree on some 'ground rules' so you can communicate in a way that works for both of you and your relationship.
- Finally - remember that healthy communication takes practice, and a commitment to keep at it. Keep working on feeling connected, talking to each other and making space for really listening and sharing each other's feelings and thoughts.





# Self care tips



## Be kind to yourself

We all have bad days when we feel we haven't quite done what we wanted, or been the type or person/parent/partner we would like to be. Accept that this was just one of those days, and that tomorrow is another opportunity to start over. Don't be too critical of yourself – think how you would treat a friend in the same situation and what you would say to them, and do the same for yourself.



## Gratitude

Research has shown that finding things to be grateful for lifts your mood and helps you to focus on something positive when things feel tough. Each day, write down one thing you are grateful for, no matter how small, and share this with others.



## Eat healthily

Try to eat regular meals that are nutritious – try to get your 5+ a day of fruit and vegetables, drink lots of water and avoid using caffeine, alcohol, drugs or medications. Fuel your body well; takeaways won't hurt every now and then, but ask friends to make meals so that you are fueling your body for the road ahead.



## Acceptance and mindfulness

This can be a time with lots of distressing thoughts and feelings; try not to fight them, just notice them and accept them as part of the journey. Some things we can't change or control – we can only ride the wave rather than fight it. Allow those thoughts and feelings to be present and let them pass.



## Keep active and connect with others

Getting your body moving helps to lift your mood, manage stress and worry, improve your physical health and give you more energy. It can also provide a break from the illness, and provide a chance to connect and spend time with people you care about. Staying in touch with people you care about is important – even via text or social media. Support is vital and people will want to help.



## Relaxation

Make time for yourself; find something that relaxes you – music, a shower/bath, reading – and do a little of this each day. Even five minutes can help your stress levels and help you unwind. Everyone is different, so think of the thing that helps feed your soul and relaxes you.



## Sleep

Getting as much sleep as you can is vital for your energy levels, your mood, and managing stress and worries. Have a look at the handout included and think about taking turns staying with your child so that you get a good night's sleep regularly. Helping yourself helps your child.



## Learn how to calm down when distressed

Being distressed is a normal part of your child having cancer; learning to calm down your feelings when you are distressed will help you feel more in control and that you can manage. Once the feeling is less intense, you can talk to people about how you are feeling and get the support that you need.

# Belly breathing for calmness

**Belly breathing is a great way to calm down when you are upset or stressed.**

First of all, breathe out through your mouth.

Next, imagine that there is a balloon in your belly. As you take a deep breath in through your nose, imagine filling up the balloon so that your belly puffs up.

Now, breathe out through your mouth (like blowing a bubble) and let all the air out of the balloon.

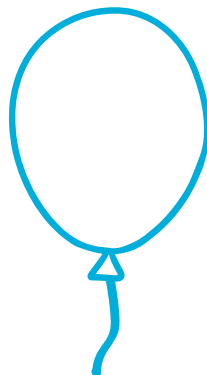
Take slow breaths in and out. Try to count to five as you breathe out and three as you breathe in.

Exhale...2...3...4...5

Inhale...2...3

Repeat until you are feeling calm.

Remember to practice every day until it becomes easy to use when you need it.





# Good sleep habits

There are proven ways to enhance good sleeping. Considerable research has gone into developing a set of guidelines and tips which are designed to enhance good sleeping and can provide long-term solutions to sleep difficulties.

Medication used for sleep difficulties tend to only be effective short-term. Ongoing use of sleeping pills may interfere with developing good sleep habits, prolonging sleep difficulties.

## Good Sleep Habit Tips

- 1. Sleep when sleepy.** Only try to sleep when you actually feel tired or sleepy, rather than sitting awake in bed.
- 2. Get up & try again.** If you haven't been able to get to sleep after about 20 minutes or more, get up and do something calming or boring until you feel sleepy, then return to bed and try again. Sit quietly on the couch with the lights off (bright light will tell your brain that it is time to wake up), or read something boring. Avoid screens or doing anything that is too stimulating or interesting, as this will wake you up even more.
- 3. Avoid caffeine & nicotine.** It's best to avoid consuming any caffeine (in coffee, tea, soft drinks, chocolate, and some medications) or nicotine (cigarettes) for at least 4-6 hours before going to bed. These substances act as stimulants and interfere with the ability to fall asleep.
- 4. Avoid alcohol.** It's also best to avoid alcohol for at least 4-6 hours before bed. Many people believe that alcohol is relaxing and helps them to get to sleep at first, but it actually interrupts the quality of sleep.
- 5. Bed is for sleeping.** Try not to use your bed for anything other than sleeping and sex, so that your body comes to associate bed with sleep. If you use bed as a place to watch TV, eat, read, work on your laptop, pay bills, and other things, your body will not learn this connection.
- 6. Limit naps.** If you can't make it through the day without a nap, make it less than an hour and before 3pm. This helps get a better sleep at night.
- 7. Sleep rituals.** You can develop your own rituals of things to remind your body that it is time to sleep - some find it useful to do relaxing stretches or breathing exercises for 15 minutes before bed each night, or sit calmly with a cup of caffeine-free tea.





- 8. Bathtime.** Having a hot bath 1–2 hours before bed can be useful, as it raises your body temperature, causing you to feel sleepy as your body temperature drops again. Research shows that sleepiness is associated with a drop in body temperature.
- 9. No clock-watching.** Many people who struggle with sleep tend to watch the clock too much. Frequently checking the clock during the night can wake you up (especially if you turn on the light or check your phone) and reinforces negative thoughts such as “Oh no, look how late it is, I’ll never get to sleep” or “it’s so early, I have only slept for 5 hours, this is terrible.”
- 10. The right space.** It is very important that your bed and bedroom are quiet and comfortable for sleeping. A cool room with a warm bed is best. Make sure you have curtains or an eyemask to block out early morning light and earplugs if there is noise outside your room.
- 11. Exercise.** Regular exercise is a good idea to help with good sleep, but try not to do strenuous exercise in the 4 hours before bed. Morning walks are a great way to start the day feeling refreshed!
- 12. Eat well.** A healthy, balanced diet will help you sleep well, but timing is important. Some people find that a very empty stomach at bedtime is distracting, so it can be useful to have a light snack – a heavy meal soon before bed can interrupt sleep. Some people recommend a warm glass of milk, which contains tryptophan, which acts as a natural sleep inducer.

*Sleep well*

# What next?

**As the end of treatment nears, people have time to think about everything they and their child have been through. Emotional reactions can resurface or start to feel overwhelming.**

Other people may be celebrating the end of your child's treatment and wondering why you're not doing the same, which can be challenging! Not all young people will reach this stage; recurrence of disease can bring a resurgence of emotional responses and distress, particularly if the disease becomes incurable. Ongoing support at this time is important.

Moving from active treatment to post-treatment follow-up can also lead to its own type of anxiety, as monitoring of your child moves to three monthly checks – the term “scanxiety” has been coined to capture the anxiety that scans and medical checks can bring. Learning to return to some form of normality can be challenging, when there is a ‘new normal’ and a feeling, for some, that they have been changed by the cancer experience. For some, ‘moving on’ from cancer and leaving it behind is their goal; for others, cancer has become part of their identity and family story, which means adjusting to being out of treatment involves looking to a future that also involves remembering the past. There is no right or wrong way to move forward; knowing what you need and letting others know will help them understand how you're managing this new transition.

While cancer can feel like a traumatic diagnosis for the whole family/whānau, we also know that some people have experienced what has been termed “post-traumatic growth”. This means that while cancer is an extremely difficult experience for everyone, later on people feel they have a better perspective on life, such as feeling their priorities and values are more in keeping with the life they would like to live.

Some have said *“I hated the cancer journey, but I feel I am a better person because of it, and my life has more meaning”*. Studies have shown that siblings, despite experiencing distress at their sibling's cancer, also show resilience and grow as people. They also tend to be more empathic, compassionate and understanding than other people their age. This can be true for the young person who has gone through cancer too.

So, while cancer is a challenge for everyone in the family/whānau, people can get through with support, and emerge with strengths and resilience. Recognising your supports and coping goes hand-in-hand with being aware of times when you might need more support.

*"It was like he'd decided that this is what's happening and he's beating it no matter what. In some ways I think that this journey has made him the way he is. Outgoing, full of life, very determined but also full of love and of course – just wanting to be a typical boy."*

Nixon's Mum.



# Using the Wellness Check-in

**The tool we are using to check on your wellbeing has been adapted for NZ families/whānau, from tools used worldwide.**

It covers all areas of wellbeing, coping and supports, as well as challenges and stresses. It's helpful to look at how you're doing and what you may need, in terms of other supports or help.

Going through the Wellness Check-In with your FSC can help you access these supports. The reason we ask you to do this is that this gives you and your FSC a chance to talk about your feelings, your supports and how you are coping, and how you can be supported to continue doing those things.

Your FSC will check in with you regularly to give you an opportunity to talk about any changes (good or bad) as to how you are feeling and coping with your child's cancer. They'll also check how you are doing at times of change, which we know can be particularly stressful.

The Wellness Check-In is quick and easy to do. You don't have to answer any questions you don't want to. It's an opportunity to reflect on your strengths and positive coping - as well as any difficulties and if you feel you need additional support with.

## **After the Wellness Check-In:**

- If you don't need/want further support, your FSC can offer you suggestions to enhance your wellbeing that you and your family/whānau can put in place and will continue to check in with you.
- If you do want further support, your FSC will discuss with you the main challenges you're currently experiencing and what the most appropriate support might be. For example, if you have identified that you have a number of practical concerns, connection to a social worker around potential financial assistance could be appropriate.
- If you have spiritual concerns, your FSC can talk to you about who you'd feel most comfortable to seek advice from.
- Other possible connections include counselling support with a trained and approved counsellor from the Child Cancer Counselling Network.
- If you would like additional support from a counsellor, the information in the Wellness Check-In will be used to complete a Referral Form to help the counsellor have a sense of your needs.
- A counsellor will be found by finding someone who best fits with your needs and location. These sessions will be funded by Child Cancer Foundation.





# Please complete the following Wellness Check-in

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Please circle the number (0-10) that best describes how much distress (mamae) you have been experiencing in the past week, including today:

0	1	2	3	4	5	6	7	8	9	10
No distress									Very distressed	

Please circle the number (0-10) that best describes how well you have coped over the past week:

0	1	2	3	4	5	6	7	8	9	10
Not coped									Coped well	

Please indicate if any of the following has been a concern for you in the past week including today:

## Spiritual/Wairua Wellbeing

- ☐ Challenges to your faith and beliefs
- ☐ Feelings unsure about the meaning of life or the purpose of life
- ☐ Asking "Why Me?"

## Practical Concerns

- ☐ Housekeeping
- ☐ Housing
- ☐ Money
- ☐ Transport
- ☐ Work/Study
- ☐ Hospital processes
- ☐ Child care
- ☐ Cultural obligations

## Family/Whānau Relationships

- ☐ With children
- ☐ With partner
- ☐ With ex-partner
- ☐ With other family/whānau
- ☐ With friends

## Physical/Tinana Wellbeing

- ☐ Sleep
- ☐ Appetite
- ☐ Changes in weight
- ☐ Feeling of physical wellbeing
- ☐ Fatigue/feeling tired
- ☐ Pain
- ☐ Concentration
- ☐ Memory

## Emotional/Hinengaro Wellbeing

- |   |  |
|---|--|
| <input type="checkbox"/> Depression   | <input type="checkbox"/> Anxiety         |
| <input type="checkbox"/> Fears  | <input type="checkbox"/> Sadness         |
| <input type="checkbox"/> Worry  | <input type="checkbox"/> Guilt           |
| <input type="checkbox"/> Loneliness   | <input type="checkbox"/> Self-confidence |
| <input type="checkbox"/> Loss of interest in usual activities                         |  |
| <input type="checkbox"/> Keeping emotions under control                               |  |
| <input type="checkbox"/> Feeling tense or nervous                                     |  |
| <input type="checkbox"/> Can't stop thinking about a specific event that has happened |  |

Continues on next page

**Parenting your child that is (or has been) receiving treatment for cancer can be challenging. Have any of the following been a concern for you in the past week, including today:**

- |   |  |
|---|--|
| <input type="checkbox"/> Feeling connected with your child                          | <input type="checkbox"/> Caring for your child   |
| <input type="checkbox"/> Managing with your child's emotions                        | <input type="checkbox"/> Helping your child with their emotions                              |
| <input type="checkbox"/> Your child's development                                   | <input type="checkbox"/> Your child's sleeping   |
| <input type="checkbox"/> Talking about the disease and consequences with your child | <input type="checkbox"/> Following advice about treatment/giving your child their medication |

**The following questions can help identify the support you currently have and help you decide if you would like/need further support:**

1a. Do you feel you receive enough support from people around you?

- ☐ Yes ☐ No

1b. If yes, what kind of support do you receive? Practical/emotional/other...

1c. If no, what kind of support would you like?

2. Do you feel people understand your situation and what you are going through?

- ☐ Yes ☐ No

3. Do you have ongoing health issues?

- ☐ Yes ☐ No

4. How do you get along with medical staff?

Very well      Well      Fair      Poorly      Very poorly

5. Would you like to talk about your situation to a professional?

Yes      Maybe      No

Please list any other concerns you would like to talk about:

Would you like us to connect you to additional support?

- ☐ Yes ☐ No

Do you give consent for this information to be shared when we connect you with additional support?

- ☐ Yes ☐ No

# Self care plan

**WHĀNAU/PEOPLE IN MY LIFE  
CONNECTION & SUPPORT**

**BODY/TINANA**

**MIND/HINENGARO**

**SPIRIT/WAIRUA**





Notes:



A series of horizontal blue lines for writing notes, spanning the width of the page.



**Contact us:**  
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