

Growing around grief

Kā tipu ake i te pouri

Parents talk about
life after their child died
of cancer.

*Kā kōrero ngā mātua i te
ōranga, i muri i te mate
taurekareka o tā
raua tamaiti.*



*We would like to thank the parents who
generously shared their stories for this book.
This book is dedicated to their children.*

*Ka mihi ki ngā mātua i whakatohatoa ā
ratou korero mo tenei kaupapa. Kua whakatapua
tenei pukapuka ki ā ratou tamariki.*

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This booklet was written by Lois Tonkin for families whose child has died of cancer.

Lois is highly regarded for her skills and experience in working with families and writing resources about grief and loss.

Child Cancer Foundation would like to acknowledge her expertise in writing this booklet and the sensitive way she has worked with the families who have so generously shared their stories and experiences.

*Kia whakaaetanga me ngā mihi ki te Kaituhituhi
o te pukapuka nei, Ko Lois Tonkin*

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Introduction *Te Timatatanga*

Becoming a bereaved parent is like joining a club that no one wants to belong to. This book is written with the stories of parents who joined that “club” when their child died of cancer. They come from all over New Zealand, and from a wide range of backgrounds. For some, their child’s death was very recent. Others joined many years ago. They have all shared the experience of hearing a devastating diagnosis, of going through treatment with their child, of coping with their death, and of grieving for their loss. They began to grieve for their child with little idea of how it was going to be, or how they would deal with it.

“So much is unknown. To try and predict and say ‘oh, this is how I’m going to handle this, and I’ve got to get on with this, and I’ve got to get back to work’...maybe some people do that and they can get by, but in my experience, your life is never the same again. You have to create a new life. And however you do that, you have to be gentle on yourself and as careful with yourself and your partner and other children as possible. And everyone’s different. I think there are some common things in all of this; but don’t ask me what they are!”

As you will see, these parents experience and deal with it in very different ways. Reading through these stories, you might find some people who have had the same responses as you, and others who have handled things very differently, highlighting the fact that there isn’t a right way or a wrong way to deal with the death of your child. They have told their stories here in the hope that sharing how it is for them will help someone else whose child has died. They all know what a lonely journey it can be.



“As bereaved parents we’ve got all this wonderful combined wisdom and it’s great to share it. It makes me realise when I look at all those people with all those pearls, how it’s so helpful and so important for our culture to keep these things going, because we never want to be in a place where we’ve lost that, where we’re not sharing it, where we’ve allowed people to become so isolated that there’s nobody to help. Or where there’s not a community to help: that it’s only a professional service. Because in reality, it’s what happens informally that makes that huge difference, and the difference happens incrementally, in small steps. It’s only when you look back that you can see, step by step by step, how it happened, how you got through.”



Grief is different for everyone

He rereke te pouri ki a tatou katoa

It would be nice if this book could be like a recipe book, telling you what to do and what to expect when you're grieving for your child. Unfortunately, it's not that easy.

"I think we look for answers with grieving. We want someone to say, 'Well, you're going to do this, this and this, and next week you'll do this, and in three months time you'll be OK.' It doesn't happen like that, but that's the expectation. I've learnt not to have expectations because it's all so different."

Grief is like a fingerprint: everyone feels it and expresses it differently. Children and teenagers may show their grief in ways you don't expect. Men and women often grieve in different ways, and may not understand each other's way. Other people around you may not feel and act as you do, but they may still be grieving.

"I had got the ideas of what grief might be like from people I had seen that had lost loved ones. I guess because my experience wasn't like what I had seen them go through my conclusion is that everybody's experience of grief is different and everybody grieves differently. I suppose it's like trying to describe to someone what labour and birth is like: no matter how many people tell you their experiences of that, your own experience is never like what people have told you. I think that's probably a good analogy with losing a child and the grief afterwards. Nobody can tell you exactly what it's going to be like for you."

For many parents, the first months or even years after their child's death are very difficult. There are constant reminders of their loss.

"I would get in the car and just fall apart. I would cry and cry. Then I'd get to my job and put on the other face and get on with it. I think everybody does what they have to do. You do what you can do, and you do the best you can. I would cry every day for probably two years. I remember feeling the loss was so enormous; even doing all that crying was just like putting a toe into a huge lake."

"There are the things that you notice in your daily routines. For instance, I used to make a short journey from work to home which took a maximum of 15 minutes, and every day for a long time I used to get to a place in the road where I would be overwhelmed with the whole grief of the situation. I would just be absolutely overwhelmed. And then.... it stopped! It was probably a matter of months to get to that point, and to be able to get home intact! And there are all those little stages that you have to get past, and they are so individual to a person."



Other parents are surprised to find that grieving for their child is not as bad as they expected it to be.

"Before he died, I expected the time after he died to be quite traumatic or hard to deal with; I didn't know how I was going to cope. It's very scary when you know you're going to lose your child, because you've just got no idea what to expect. But it wasn't as bad as I thought it would be. In fact, Child Cancer Foundation ran a course for any parent with a child that had cancer or had had cancer, and we went to that course because I felt like I was coping too well. I thought maybe there was something that hadn't come to the fore, because everybody said to me, 'Oh, you're coping so well!' and I thought, 'is there something wrong with me?' So we went to the course, and we walked away thinking 'we are coping alright', and I think that maybe because I'd had these thoughts that it was going to be really hard to cope with, it wasn't as bad as I had thought. I'd expected myself to have periods of having floods of tears or just missing him terribly, and I suppose there was a bit of that right at the beginning, but not now."

Many parents find that the way things were during their child's illness has a big impact on how they grieve after their child has died. For some people, there is very little time between the diagnosis and death.

"We felt like we'd been through a rollercoaster ride. It was so up and down. We had the devastation of the diagnosis and then the hope that maybe the radiotherapy would help. In the nearly three weeks we had between when he was diagnosed and when he died we just went up and down. He'd be down in the hospital and then he'd come home for the weekend and he'd be good and we'd think, 'Ohh... maybe....' For the first few months after he died, we were just in shock really."

Others have spent many months with their child struggling with pain, invasive treatments and misery. They may spend the first part of their bereavement trying to come to terms with the horror of their child's final illness.

"I don't think anybody can ever be prepared for what your child goes through. I know that not every child has the same thing but palliative care was huge for us, and pain was huge. And I think that I could never ever prepare anybody for what she went through because it was just awful. Her suffering at the end was horrendous. You hear about all those lovely things about people dying, but oh God it wasn't like that. I couldn't ever have imagined it would be as bad as it was. My greatest fear was that she was going to die in hospital and because she had severe pain she had to have an epidural put in and it meant that we had to go back to Starship every time it came loose. It was my huge fear that she would die at Starship, not at home. Thank God, she did die at home. I think when you're preparing for the death you have this image in your mind about how it's going to be and often it may not happen as you imagine it."



"The last two years for her were horrible really. The chemo played up with her and she had lots of other issues going on besides cancer: she felt ugly and fat and terrible, all the usual teenage stuff. Then she went into the hospice, to get on top of her pain and because her kidneys had packed up. We expected her to die, but she ended up coming right and we had her home for another four and a half months."

"Even though it's been four years since she died, looking at photos of her, I find it hard to believe that she got that sick and died. Still that feeling of almost an unreality. She'd come through against all odds before, so it was really hard to believe that this time she didn't."

Grief is much more than just sadness

He nui noa atu te pouri i te pouri

Parents talk about a huge range of feelings about their child's illness and death. It's normal to feel very angry, lonely, numb, forgetful, scared, guilty, betrayed, lost, empty, depressed and much more. But many parents also talk of a feeling of relief, after being with their child through a lot of suffering.

"For us the last time she relapsed she had been through so much that it was a relief when she died to be honest. We were just thinking, 'Oh please, just hurry up. You need to die. This is just not good.' We probably only had three months of really intense illness, but we were ready for her to go, and I think you sometimes get round the process a lot before these children die. We did so much of our grieving in that time. I don't know about other people but for us, I don't think we started grieving the first time round – we were all very positive – but by the time she'd relapsed the second time and subsequent times, the grieving definitely started at that point. That definitely helped when we were dealing with her death. I don't think I felt as bad as I thought I would do after she died. It was a huge relief. I think I spent a long time thinking that a huge burden had been taken from our shoulders. Even now I still don't think it's ever been as bad as I thought it would be."

"We had about two years with him in terminal phase I suppose you'd call it. I actually think that having that length of time knowing that he wasn't going to be around forever gave me time to grieve before he left. In fact I probably had quite a bit of tears and stuff over that two years and I think when he actually eventually went I was so relieved of the burden of caring for him that there weren't actually much tears. I cried a lot at the funeral, but not much after that. I felt like I had accepted and grieved a lot during that terminal phase. I suppose I've always viewed it quite positively: I see other parents who have lost their children with very little or no warning and I feel that I've been quite lucky to have had two years."



The feeling that their grieving has begun before their child died is common to a lot of parents. Some say that spending time with their child during the long months of their illness, or doing something for them, helped them when they were facing bereavement.



Many other parents talk about feeling guilty about the fact that their child had suffered so much, or about decisions they made or things they couldn't change.

"Having that time before she died made a difference for me. There were two of us, and if you look at the way my husband coped and how I coped, I think that because I was with her, it helped. It was much different for my husband. For him it was a shock when she died whereas I had been through it with her, and I'd talked to the nurses who came through here to help us. They kept me abreast of what I was likely to see. All those things prepared me. I was very aware of what was going on with her whereas my husband, who was still working, didn't experience it in the same way. Because I was with her all the time, I tried to anticipate what she needed. I tried to attend to her every want and every need, mentally and physically. I was just there for her, and that helped in some ways. I had a very close relationship with her. I knew that I was preparing her to die. I don't think I consciously did it, it was on a different level, but at the end of it I had done a lot of my grieving. I was hands-on, and at least that way I could make her something, entertain her or comfort her, or do something for her."

"Our daughter planned the whole funeral, and my father-in-law and I built the coffin and did heaps of other stuff. She knew what was happening and what she wanted. The whole process of doing what she wanted, and being involved in doing it helped a lot, and made wonderful memories that we hang on to."

"It's very difficult because you don't know what the right thing to do is. For a long, long time after he had died, I really beat myself up because I never told him he was going to die, and I felt very guilty. It took me a long time to come to terms with that, it really did."

Anger is a very common feeling, especially for bereaved fathers.



"I felt the grief most in my fists. I just felt so angry nearly all of the time. I was working as a milkman at the time, and I remember I used to hope someone would take to me in a dark alley some night out on my run because I was just hanging out to punch someone's lights out legitimately. Being so angry caused a lot of problems with my wife too because she didn't know how to handle it, and where she felt sad and tearful, I was just full of rage."

"I could have had a real issue with anger if I'd let it. I found that it was just too destructive to let that happen. I go to the gym three mornings a week and I can see something positive for that because I actually feel better. I also like to get on my Harley sometimes at night and give it beans!"

You feel grief in your body too. People dealing with a big loss often notice they are affected physically. They may have trouble eating and sleeping, or feel sick, tense and shaky, aching, exhausted and cold. Panic attacks are common. Sometimes parents describe it like having a chronic bout of the 'flu.

"In the early weeks and months after he died, I didn't really cope. I cried lots. I was just so sad. It's such a physical pain. It's a pain you just cannot imagine and when people say, 'Oh I know how you feel,' you just want to slap them in the face. They have NO idea. They really don't. You know, I've been one of those people myself that have said that, but until you've been there yourself, you just can't know. The physical pain was... it just hurt so much! In my chest especially. I just went to bed crying, I woke up crying, I mean for weeks I'd wake at the time that he died. For weeks on end, I just looked at that clock and remembered every moment so vividly."

"Grief is exhausting. It has taken a long time to feel an energy for life again."

"Ka mauui te pouri. Kua roa te wā kia rongo i te kaha o te ora anō"

Trying to make sense of it all

Ka hanga tikanga o te katoa

At some point, many parents ask themselves why their child developed cancer and died. For many parents, the first few months and years are spent trying to come to terms with what has happened and make sense of it all.

"There's no meaning in this for me, I don't understand why it happened, and I do still say, 'Why was it us?' and that's the hard thing to accept, because there was no reason why. The only thing is that I now think we were lucky to lose him to cancer because we had a reason: he had a brain tumour. I don't know why he had the brain tumour, but he died because he had that. But when you hear about murders of young children, and fatal car crashes and I think, 'My God, that is such a waste!' Those families must forever be asking: 'Why did that happen?'"

"We met quite a few kids when she was sick, and they were all kids that you knew were only here for a short time. They were special. They had a lot to give, and a lot to teach people and you learned from them and you knew that they were all going to be called back home sooner than you wanted them to go. They were angels that were lent to us for a short time. That's how I've coped; by seeing it in that way. That's a realisation after my daughter's death that helped me to make sense of it."

People talk a lot about the need for 'acceptance' when someone dies. For bereaved parents this idea can be very difficult. They feel like they're between a rock and a hard place. People tell them that unless they 'accept' it they're going to suffer for the rest of their lives, but 'accepting it' seems to mean that it's OK that their child has got cancer and died, and for many parents, it's not OK at all. Many parents say they don't want to 'accept' that their child has died, because it should not have happened.

Accepting that your child has died from cancer doesn't mean you have to like it. Though you might be able to find silver linings for this cloud sometimes, the fact remains that it is a cloud. Sometimes life doesn't make sense, and it isn't reasonable or fair. You don't have to feel good about this, but facing the fact that it's true so that you can get on with doing your best to deal with the situation, does make things easier. Some people find this easier to do than others.

"I never ever asked myself, 'Why us? Why did she get sick?' and those sorts of questions because I've always had a strong awareness that everyone has these challenges. There's just not one person in the world who does not have these really difficult and challenging experiences in their lives."

Sometimes parents feel that as long as they keep fighting the fact that their child has died, there's a chance it might somehow not be true. Other parents say that it gets easier to deal with once they let go of asking "why" and realise they might never understand why it has happened, but it has.

"I think that my family experiences and the support, and the fact that I have always been a 'cup-half-full' person, has brought me to this place that I'm in now about all of this. I think that some people make a conscious choice to take what they can from this rather than be diminished by it. Because in the end, that is a choice."

What do you expect grief to be like?

He aha te tumanako o te pouri

People often have the idea that grief is something that makes you feel really sad for a few weeks or months, and then you come to a point where you accept your loss, get over it, move on, and feel better. In the past grief has sometimes been described as a series of stages to go through – shock, denial, anger, bargaining, depression and acceptance – before life ‘gets back to normal’.

The fact is, it's not like that for most people, especially when a child dies. Some people never experience some of these stages, and others come back to them again and again. Others feel things that aren't on the list. Most parents do talk of their grief changing over time though and are aware of milestones they pass along the way.

"I think when I look back there were milestones in terms of being able to talk about what happened with a little bit less emotion. It's all those firsts; getting through them and getting to the next stage. I used to go out and about and there were always people who didn't know and that's hideous. You have to explain, and you have to make them feel OK because they're shocked, and they feel bad that they didn't know and they've said something now. So it's getting to that stage where you can tell the story and you don't become overly emotional. That's a real milestone. It's more to do with the frequency of the telling, rather than time passing. Telling it again and again softened it a little."

It can also take longer than you expect. You don't have to 'get over' the loss of your child. Most parents think of it more as coming to terms with it. With a big loss like this, you may find it hard for a long time, and it may continue to touch you from time to time for the rest of your life. In the months and years to come, a smell, a song or an anniversary can remind you again of your loss for a while. The death of a child is something you try to get used to rather than get over. Your aim is to find ways to live with it; you don't have to like it.

"It's been five years, and now it's much better. It's peaceful – I think that's the word. I'm at peace with it. It's still hard of course, on special days. But I don't want to be there with him so much. In the early days I just wanted to die. I really did. It's hard to say that but maybe I need to."

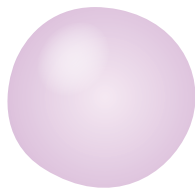
"My understanding of grief and how that all works has changed a lot. Someone made the comment to me that when you're going through this there's no right way to feel, or wrong way, and I kept telling myself, 'You don't have to get it right!'"

The Circles of Grief

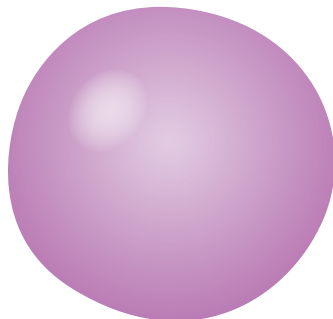
Ngā porowhita o te pouri

This way of looking at growing around grief is one that grieving parents have found useful for years. As far as we can find out, no one knows where it came from originally.

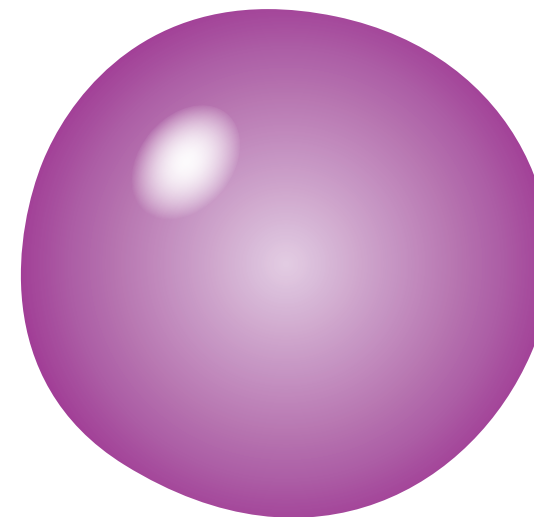
Imagine your life is a circle. When your child first dies, or maybe at the time of diagnosis, your life becomes completely shaded by your grief. In those first weeks or months, it's hard to escape your feelings of loss. They're there first thing when you wake up, they're at the back of your mind as you go about your day, and they're there on your mind and heart when you go to bed at night. It's hard to imagine that you will ever feel any different.



Many parents believe that, over time, their grief will shrink, and become something they can manage: a smaller part of their life. They don't usually think it will go away completely – this is after all their child that has died, and you don't forget your child – but they think it will become something they have a handle on and feel in control of.



But something else happens. As time goes by, other people and other situations come along, and your life grows around your grief. You find yourself taking pleasure in things and feeling enthusiasm for life again. It's not that you 'get over' your grief or that you have forgotten your child, or even that they become less important to you. It's more that their life and death becomes part of who you are. Most days, you live in the sunny part of your life, but there are still times when a photograph, a smell, a song or an anniversary can remind you of your loss, and you find yourself back in the shade for a while. This can happen 5 months, 5 years or even 50 years after the death, and is a natural response.



"That circles diagram of the lady who had lost the child made a big difference for me. I haven't forgotten that, and I've often thought how true it is, because that's how it was for me. That pain's still there if I really want to think about it; that special place in my heart is still there, it hasn't changed. In fact, you know I wonder if my love for him hasn't grown?"

Changes in grief over time

Kā huringa te pouri i runga i te wā

When your child first dies, it can be hard to adjust to the way things have changed for you. Many parents whose lives were disrupted by long trips away for treatment find it hard to settle back into their life again.

"When you've got a child that's sick for a long time - not even just when they're dying, but also when you're on treatment right at the beginning - your whole life focuses just on that, and you come out of hospital and sometimes suddenly there's nothing there to focus on anymore. I know that lots of people say that when you finish at the hospital, and you finish your treatment, it's almost like, 'What do we do now?' So when she died, I didn't realise how much our life had been on hold. The threads of life aren't even there to pick up from where they were. And your whole way of living is different. For example, the biggest thing I found was that I could actually plan things. I still sometimes find that quite hard to get my head around that. I can book a holiday that's three or four months ahead and know that we're going to go on it. Whereas before, I remember doing stuff like that and something would happen and you never would do it. When she died, we had to reconstruct a life."

"I stayed away from work for about 3 years. It wouldn't have taken much to force me to stay at home for good! I had to go and do a retraining course and I felt quite good doing that because I could do it from home! At the end of the 3 months they said, 'Right, now you're ready to go back and work as a teacher,' and I said, 'Oh my goodness, now I've got to do it!' I felt like I had to step into the big wide world. I did it very cautiously. In the first term I think I only had two occasions when I went out and taught and that was a big thing for me. And then the next term I did a little bit more. And then in the third term I went in part time. Then I had the realisation that I'd left home, and things were going to change, and I'd just have to do it. It's fine now, but the one thing I still find hard is that I teach at a Māori school, and each year we have a pōwhiri for the new five-year-olds. The one thing my daughter wanted to do when she turned 5 was to start school but that never happened, and I still find it very emotional going to that pōwhiri."

For most parents, the process of things getting better is such a gradual one that they barely notice it happening.

"I used to wake up at the same time as he died for ages. And then I remember one day thinking, 'Oh my goodness I didn't wake up at that time today'. And then all of a sudden, I thought, 'Oh, it's been a week and I haven't done that.' And that's how the process went. Just suddenly time went by, and it got easier. It was months though. It was three years really before I could talk about him without crying."

For some, feeling better comes in patches.

"During the last two years I have had periods of time where I have had to have counselling for healing. This helped a lot as the counsellor knew my daughter and I found talking to someone who knew her was a lot easier. I found I moved forwards and backwards in grief."

Some parents talk of things just getting steadily better after the death of their child, but for others the second year can be a hard one.

"After she died, initially, to tell you the truth I was quite numb. For me it was the second year after she died that was the hardest. I go to the Child Cancer Foundation Remembrance Day each year and I remember on the first year one of the other mothers said I looked quite well, etc., and then she said, 'This is the first year though. After this it hits you.' I didn't really know what she meant, but the second Remembrance Day I went up to her and told her I'd had a hell of a year the second year! Our first Christmas was absolutely terrible; only three or four months after she'd died."



"You never know just how you're going to react. As first we were numb. I look back on it now and think, 'Numbness was great!' But my wife and I made a commitment to each other that we wouldn't let it get to us and it didn't. Our marriage is a hell of a lot stronger for it. But though you plan for it, you never know what it's going to be like until you're doing it. And what I didn't realise was that it got a hell of a lot worse before it got better. It's only now, two years later, that we don't cry each other to sleep. It's begun to ease up now."

Many comment that they found it very hard to begin with, but it does get easier.

"I always remember something that a close friend of my mother's wrote to Mum to tell me after our daughter died, and it sticks in my mind so well. It was that it does get easier. She had lost her son in a car accident. In some ways that was the best piece of advice anybody could ever give to anybody. I just hung on to that in a way. It was part of a whole kind of mosaic of things that people say to help you through that situation I suppose."

It seems that most people in the world expect parents to 'get over' the death of their child at some point. But parents who have been through this before say you never 'get over it'. They talk instead about 'getting through it'.

"It took me a long time to get past those last few months. The vision of her in those last few months stuck with me for a very, very long time and I couldn't get past that whole thing where every time I closed my eyes I saw her like that. For a while I couldn't remember anything else about her; I couldn't remember anything other than the sickness. But that passed, and now I remember all the good things. I look at her time and I think her life was amazing really; how she fitted all the stuff she did in. There are only a few times that upset me now. Times when I see her friends who are at college and are doing this and that and everything else. I find that quite hard to deal with. And I think that's from that whole thing of the broken dreams. All the dreams you had for your child. How it might have been. 'If only...' I look at that for my other kids too: 'I wonder what it would be like if she was here, and what they would be like together?' But to be honest, it hasn't been as bad as it could have been. I think we've come through it really well."

"It's been just over two years and now... I just don't think about it. It's just too hard. I mean you go over it and over it and it doesn't change anything. I still walk past our daughter's room and think, 'How did that happen?' I still think, 'It would be nice if she just came through that door. One more cuddle, and then I'd be happy with that.' But... that won't happen."



As time goes by bereaved parents become more aware of the ongoing losses that don't end.

"The grieving never really stops in a way. Every celebration that you go to, every event of friends: you know that there's not going to be the 21st or the wedding, or girlfriends. Most of all I think I just miss him, seeing him grow into a man. You lose a life; all the normal expectations of what will happen."

"The only thing I have problems with now is the classmates my daughter had, living it up. I love them, dearly; they're a great bunch of girls. They text me and say, 'We're having a great party. She would love it!' I mean, I've got great memories and I wouldn't change it for the world, but I'll always have a problem with that. It's just the way it is."

Sometimes parents feel guilty when they start getting involved in life again. It can feel almost like a betrayal of the child that died; as if feeling happy again means that you don't care that they aren't around anymore. Part of you wants to move on and feel better and another part wants to stay with things as they were; as if holding on to your grief connects you in some way with your child.

"It's nearly two years since our son died. We had a baby at the beginning of this year and it's been good for us. It's given us something else to focus on. I think after he died there was an initial shock and just suddenly a big gap there; just everyday little things like going to the supermarket, having to shop for one less of everything or setting the table and there's one less place to set. And then we sort of got used to that but - I don't know if you could explain it as a gap - but it's just that our thoughts always drifted back to him because he wasn't there. But then after we had our baby this year all of a sudden our thoughts are not always shifting off any more. I almost feel guilty that I haven't had the time to think about him as much as I did before the baby came, but at the same time I think for me it's been good for me."

"It's coming up to six years in January. Sometimes it seems a long time, but sometimes I can't believe those years have flown by to be honest. I don't know where they've gone."

How are relationships affected?

Pēhea te paanga o te whanautanga

Bereaved parents who are in a relationship sometimes feel concerned about how the stress of the illness and death of their child will affect their relationship.

"I remember someone saying to us that a high proportion of marriages split up after the death of a child and thinking, 'That's not likely to happen to us because we have such good communication, and love'. But it has happened. And I think in hindsight over the nine years that part of the reason – not the whole reason – is that there's just too much sorrow to carry on. Our relationship brings with it heaviness. A weight that, for us, was part of the reason. The guilt that you feel, which is totally irrational. We became very brittle with each other. I think your heart closes up."

For one couple, knowing how their daughter who had died would react if their marriage didn't survive was part of the motivation to make sure it did.

"You see couples going through this who don't cope, and you see others that have, and you think, 'Well, what have they done that made life that bit easier for them?' At the end of the day, our daughter would be devastated if we didn't cope. That's probably the biggest motivation that we had. We've certainly learned from it. And our daughter always said, 'Don't spend the rest of your life being sad.' It's made us feel alright about beginning to feel better. There are times when it's way too hard, but as time goes on, the times when I'm feeling better certainly outweigh the other times."

It seems that couples make active choices about how their relationship will handle the loss, just as they make choices about how they grieve as individuals. Some couples make a conscious decision to survive and grow through the experience.

"We made a pact together that we would survive this as a couple. You can either give in to it and let it bury you or you can say, 'Right we're going to fight this and no matter what happens we'll survive it.' And that's life isn't it. People make up their mind that they're going to be a success in this life, or they just let it slide."

One of the things that makes it possible for couples to pull together is the ways they acknowledge that the other person may be grieving differently from them.

"My wife and I did it together. There were different ways in how we looked at things, but we were always in agreement about how we did it. It pulled us together rather than pulling us apart."

"My husband and I grieve in very different ways, but as a unit we've come through it amazingly well. He's had probably more problems as he's needed counselling and become quite depressed at times, and that hasn't happened to me. There were a lot of issues that came out that were not related to the death. The counsellor helped him through those times, and they were very short periods of times, I'm talking maybe a couple of months at a time. It only lasted for a year, probably quite late on. But we decided to move, and since we've moved house, the problems have gone for him, so that's been a godsend. I don't think you can move on without your child, but it was like moving away from those feelings that were tied up in that phase in our lives. He just seemed to be bogged down by the house. It's wonderful now."

For others, the difference in ways of grieving can be very difficult and can lead to hurt and misunderstandings.

"I certainly grieve differently from everyone else in my family. No one grieves like me! Oh yes. With my husband it's been very difficult. My husband is very different from me because he holds everything inside. We battled with that for a long time. So many fights and arguments. There really was. Because I'd often say, 'You lot have all forgotten him. You just don't say anything so you must have forgotten about him.' And he'd be hurt by that. He'd say 'No I haven't. It's inside!' Of course he couldn't stop and do what I was doing. He had to get back to work, had to pay the bills and do all those things. But oh, I struggled with it. I felt like I was left alone; that I was the only one doing the grieving and everyone else was just carrying on. It's very hard from the woman's point of view."

Women often comment that men don't feel comfortable talking about the loss.



"My husband didn't really talk about it to me much during the time our son was terminal or even after he died. He was always there, always available to come home early from work, or if we were having a bad day he'd come home. But he didn't speak to me about feelings or anything. I always put it down to a male thing. We share the same philosophy about it, but we never discuss it. We just work along together so I guess we must do, but we never really dissect it. I think we've both come through it well."

"My husband and I grieved very differently. I had very good support network, and I think that he didn't. I just don't think men do have them, although he plays a lot of sport so he had men around him, who were definitely there, but they found it difficult to express. Although he did have one friend who lost his wife not too long after our daughter died, and I think that friend was the one person who would approach it with him. So that was very helpful. They don't see much of one another now because the friend now lives overseas but they still like to take the opportunity to make that link when they can, which is a wonderful thing, because it's not something that men do very readily."

Their partner's sadness and distress can be very hard for men to be around. They may feel helpless because they can't make things better for her.

"It's hard. You're lying in bed there and you know your wife's crying her eyes out and you feel totally helpless. But then you think; 'Now hang on a minute, all she needs is a cuddle.' But of course, us guys think we have to fix it by doing something and you can't!"

Sometimes cultural differences mean that one partner has to learn to accommodate new ways of doing things.

"The main impact on our family is that my husband is Māori. I've had to learn about the tangi and that side of things. It was a learning experience for me but I'm very happy with it. I felt really comfortable with how all of that has happened. We had some difficulties though because we were going to get our daughter cremated and didn't really because her nanny was so much against it, being Māori. That's my biggest regret; that she was buried and that I wasn't stronger about it at the time. I've got a lot of friends who have their child with them in an urn, and I'd like that. I think that feels good to me. It was a big thing at the time, but now I'm OK with it."

Bereaved couples are sometimes so tied up in their own grief that they don't have the emotional energy to be there for each other as they'd like to.

"I don't think that husbands and wives are necessarily the best people to support each other. In fact, we spent the first Christmas after our daughter died with our own families. When I look back it seems such a strange thing to do, and yet, we needed to. I think we just felt the need to be – I don't know – just be kids again and be wrapped up and not have to look at one another and be reminded of how awful it was!"



What helps?

He aha te awhina?

When a child dies, it's easy to feel as if you are a victim of a terrible event that is out of your control. It's important to realise that you can take control over how you deal with this loss, even though you had no control over it happening. You can make choices about how you deal with it, and different things help for different people.

Both letting yourself be with the pain of your loss and distracting yourself from it at times are important ways to cope with it (see The Dual Process Model of Coping with Loss on P.32). The parents who share their stories in this book have found a wide range of strategies useful. For some people a break away can be really helpful as a way of getting away from their grief for a while.

"We ran away after she died. We went on a holiday. We only had one baby at that point, and she'd had a horrendous time of it really, considering she was only 18 months old. We just got a campervan and we just went. It was lovely. It was so nice to get out of the house. I don't know what we did, to be honest. I couldn't tell you that we went to this place and that place. We just spent time away for a couple of weeks. I think because we'd had so many people in and out of the house for those couple of months beforehand, and so many people visiting and so many people doing some amazing things, it was just nice not having to worry about other people. I think people would have kept coming, but I think – enough is enough! It was very hard coming home though."

Others also ran away, but did so because they wanted time to be with their grief.

"It's also important to take some time to be alone. I went to a place where we'd spent a lot of time as children, and I spent time alone there. It's both a painful and a helpful thing. I think sometimes a place can be very healing. It's amazing to me how everything is so connected. We reach down into our being to find the place or something that will be helpful. I went for a week, and people came and visited me, but it was incredibly quiet; it's an isolated beach and there's nothing there! I was in a friend's beach house and I just had some time to just be there. When I look back it was perhaps quite a strange thing to do and yet, obviously, a good and very healing thing. Whatever is helpful for people; if they can just find the place or find the way. It will be there."

Some parents have found that doing something for someone else is very helpful for them.

"I really threw myself into Child Cancer Foundation and then into CanTeen. It really helped. I lived what I would have wanted my daughter to do, through those kids. They were all amazing kids. I felt like I was giving back to people that gave to me. It was great. Doing something was helpful for me."

"I do other things, like I work at the Hospice shop. That helps."

"The other fantastic advice that my mother gave to me was: 'When you're feeling really low, go and do something for somebody else.' That is just the best advice that you could give to anybody!"



Keeping busy is something that helps for many parents.

"I worked. I worked non-stop from the time she died until the day my son was born, five months later. I just worked and worked and worked. I'm a teacher, and going back to school where she had been to school and facing all those children and all those parents probably was actually really good for me. It wasn't good for my preschooler; not at all. But I spent that time thinking about me I guess, and being very, very busy. I remember being so, so busy and then when my baby came along I was ready to stop, and I haven't worked since then."

Many parents find that expressing their grief through crying or writing a journal is really helpful.

"For the first few months I used the Internet a lot. I read lots of really sad things – poems other bereaved parents had written and things like that. It is nice to be sad sometimes."

Some parents whose children had died some time ago have found that the best way to deal with the waves of sadness that come over them from time to time is just to ride them through.

"Four years down the track, it's still very real. The pain of it is still there. Sometimes you just have to sit and go through it; be with it."

Some people find bereavement groups very helpful, while others try it out, and realise it's not their thing.

"I go to a bereavement group, which helps me. It gives you a place to talk about things and I realise that little things that I feel on certain days are quite normal. It puts it into perspective."

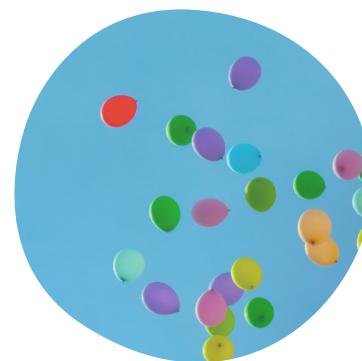
"When the bereaved parents support group started up my husband wanted to go and I said, 'Well I don't feel the need, but you go.' He went a few times and he actually found it quite helpful. He found it useful to hear other people's stories; that they were going through the same thoughts and feelings that he had been through. He probably did a lot of talking there."

"There are some things that don't help for me – I went to one of the memorial services one year and I just thought, 'No, I won't do this again.' And even collecting for Child Cancer Foundation one day in town was so much harder than I anticipated, so I thought, 'No I won't do that again!' They weren't helpful for me. For some people the ongoing group thing is really great, but obviously it's not a good thing for me."

"When the bereaved parent groups started, I went along. And even after all that time – it must have been three years after she died – it was good to hear that other people were feeling and had felt the same way and had the same issues. It was amazing how many things got rehashed up and actually were really good to talk about. It was a lonely journey at the time we were going through it."

"A few years after his death, Child Cancer Foundation organised a weekend away for us with three other couples. We were totally looked after – no cooking, taken out for dinner – and given the opportunity to talk. There was a dads' session, a mums' session and a joint session. It was fantastic to be with other couples who'd been through the same loss. It felt like a great release to be able to be frank and honest about our feelings."

Talking to family and friends is a big source of support for many parents.



"I talk to my husband, and I talk to our boys and friends about it. We always have a meal together on her anniversary, and on her birthday, and we had a little 21st birthday for her with just a few friends, and we went up to top of the hill from where we live and we let a whole lot of balloons go. I think we just remember her a lot. We remember her in our conversation, just as part of the family. I don't go to the cemetery a lot; I find it hard to go there. But when I do I buy a packet of little sparkling hearts, and I throw them on the ground, because I think she was such a sparkly number!"

"Talking to my wife makes all the difference for me. She's the one that I share the closest with. And my faith. But sometimes I don't feel that helps because I'm hurting terribly. It doesn't go away."

Talking to other bereaved parents is the most useful thing for many parents.

"The biggest help to me was meeting families who are going through the same thing or have been through it. I never forget one guy, right at the start, who rung me up out of the blue. And he said, 'In the middle of the night you might need someone to talk to. I'm another male that's been through it, so please ring me.' I'll never forget the guy. I never rung him, but I knew I could. I knew there were people there that wanted to help me, having been through it. That was the biggest help."

"The reason we've survived it is because we've got to know so many families that were going through it and we've made lifetime friends. Basically, you can ring them up now and bawl your eyes out or do whatever you want to do and you know that they know exactly where you're coming from."

"That's where Child Cancer Foundation is so amazing. We have had such amazing support. Five years down the track there's still someone who rings me up to see how I am. So we are lucky – if you can say we're lucky – that he died of cancer. I think you get to a stage where you have to try to think that way."

Not every bereaved parent is helpful though.

"It's very hard if you talk to people who are very morbid and sad. You have to keep company with people who like to live life."

Men often find that doing something is helpful for them. For one father, making a garden in memory of his son was a healing project for him.

"My partner poured his grief into his garden. We were living in a beautiful property, and when we moved there was an area that my son had helped him to excavate. So it was his dedication; to create that. Every night he would just go down there and work."

For many families, having another child is immensely helpful.



"It certainly has been a big healing thing for me having more children, although when I found out I was pregnant it was difficult. You know, everyone was so happy, and I was so sick and then when everyone was saying it would be so great, 'You'll have a baby; you've lost your son but you're having a baby!' I wanted to scream and say, 'But I've still lost my son! It's not going to take that pain away.' I think people didn't understand that. And it's been tough because we had twins, but I don't know what would have happened if I hadn't had them to be honest. I really don't. I think my life would have been very different and I would have been a different person. I wonder sometimes if I would have been here."

"Having another child helped hugely for us. She was another focus, and we had to throw ourselves into it, and I think it saved us, in a sense."

Many parents realize that the key to adjusting to the death of their child is in their attitude to it, and they make the choice to be positive about it.



"Of the families we've met, there seem to be those that think they're a victim of all this, and those that think 'OK. How can we make this into a positive?' We mixed with those ones. We didn't mix with the ones whose attitude was 'We're victims here. Help us.' We cut them loose, because it was just too hard."

"My strategy for coping is the way I think about it: I think for me that the time that we had with him was really special while he was here, but now that he's gone, that's a chapter of my life that's now finished, and I still have to live my own life. I've still got the rest of my life to continue."

"I come from a very upbeat family who were really always positive, and that gave us hope. I'm absolutely convinced that people's philosophy of life has a big impact on how they grieve."

The Dual Process Model of Coping with Loss

Te tauira tukanga rua ka whakaea i te mate

There are two key ways of dealing with a big loss.

Loss

The first way focuses on confronting and being with your loss; it includes letting yourself experience and express all the feelings of sadness, fear and anger by crying and raging, talking or writing about them. It also includes the little things parents do to keep their child close; looking at photographs and videos, keeping their room as it was, avoiding changing anything about their lives. It can mean taking pleasure in remembering or feeling the loss very painfully. Often women feel most at home with this loss-orientated way of dealing with the death of their child.

The second way is more focussed on avoiding the pain and moving on from the loss. It includes making changes in your life that acknowledge that things are different now, taking on new roles and relationships and creating a new life for yourself. It also includes all the ways parents distract themselves from their loss and avoid grieving. Keeping busy, working hard, and throwing all your energies into a project are part of this way of dealing with it. Men are often most comfortable with this way of dealing with the death of their child.



People who work with grieving people have found that the most effective way of dealing with loss is to do a bit of both of these ways; to oscillate between these two ways of grieving. Parents who let themselves feel the pain of their loss at times and give themselves 'time off' at other times by distracting themselves are more likely to adjust better to it.

Sometimes parents might feel they have little choice about what to do; they have to get back to work, or keep functioning for their other children for example, so they throw themselves into the second way described above. If this is the case, it's important that they make time to let themselves be with their feelings of loss at times, even though it may be painful to do so. Other parents, with too much time on their hands to dwell on the pain of their loss, might find they have to make the effort to get out and do something that distracts them from it for a while.

The important thing is to find ways that both express your grief and give you time off from it. The trick is to find what works for you and do it often.

Schut H & Stroebe M: Dual Process Model of Coping with Bereavement: Rationale and description. Journal of Death Studies, Pp 197-224. Washington, April/May 1999

Remembering your child

Kia maumahara tō tamaiti

Finding ways to keep the memory of their child alive is very important for most bereaved parents, and families find many different ways of doing this. Some have developed little rituals that are comforting for them.

"To remember him we light the candle we got for his funeral, and we light that on his birthday and on special days, and if I feel I particularly need to do it at other times. We also have little star crystals that people gave us hanging around the house because a couple of weeks before he died another woman from our area lost a child and she sent me a crystal star telling me that she always had a crystal in his room and when she saw the rainbow, it was his light and she wanted me to feel that as well. So the crystals were quite a thing. I've got them all over the house!"

"I started doing scrapbooking. Four mums here through Child Cancer Foundation started getting together once a month, and one of the mums showed this scrapbooking she had been doing. It was absolutely beautiful. For her, she said it was the last thing she could do for her daughter. So I started. I did a family album, and I did an album for each of the children and now I've started one for my son. I'm going to scrapbook his whole album. It's very healing and it gives you a chance to remember the good times and think about those times and remember them."

"We have a shelf where we have family photos. We've kept all his photos that were there before he died, and they probably always will be. And then after he died we went through all his things and we got a box out and kept all the things that were special: things that we felt were really significant and that were really him, symbolic of him. We always keep the channels open so we have no hesitation mentioning his name in the family, and I think because of that the boys will spontaneously talk about him when they feel like it. Usually on his birthday we make a point of going out for a meal because that was something special that he liked and he enjoyed, and then whenever we feel like it we'll go to the grave. Often that will be at the boys' suggestion."

"My husband had a box carved for her ashes and in the first year he would sit it on the bedside table on his side of the bed, and he would wake up in the morning and take her box out into the lounge and each night he would take her back to the bedside table again. I don't know whether that was a good thing or a bad thing, and he doesn't do that now, but initially that was really important to him."

Some families have problems when one member of the family finds remembering too painful, but they find ways around it.

"Sometimes I feel we should do things to remember her, but I'm also aware of my husband, and I try not to do things that get him morbid. He has such a hard time, and he wouldn't even celebrate Christmas if he had a chance. So I get the tree out, and the boys and I go looking for special Christmas tree decorations. We've got her photo that sits on the tree and we have a few angels. Our tree has probably got more angels than most people's! And we've just started buying something - a girly present - and we go to the Salvation Army and put it under the tree there. Her birthdays are hard. Her Dad gets really upset. He takes the day off work so it's just him and I, and we spend the day together. We did try watching a video initially, but I don't think it was a good idea. It sort of set the tone for the rest of the day. So we try to go for a walk or something and just spend the time together. We don't do the same thing each year but just try to get through."



Where does spirituality fit in all of this?

Kei hea te pai wairua i roto i enei mea?

The death of their child causes many parents to look at their religious and spiritual beliefs. Issues about the purpose of life, and what happens after death become more important. Finding some meaning for what has happened is very important for many parents. Some with a strong religious belief find that faith strengthened and comforting.

"I think our spiritual beliefs have definitely made a difference in coping with it. Sometimes I can feel his presence and to me that soothes me to know that he's in a better place."

"My faith makes a big difference to how I cope with this. We believe that her body's in the ground, but her spirit is with God. We all believe that. We never stop missing her; you just don't stop missing your child but knowing that she is with God and that we will be with her again one day just transforms it, because of what we can look forward to. Sometimes I feel her with me. Sometimes I've said I feel as if she's hugging me. "

"I have to say that being a Christian is really important and knowing that I will see her again is really important and valuable. It's strengthened my faith. Some people have asked us how that can be; that God would take our child like that. But life isn't fair. And I know that we all have to die, and I don't have an answer for why she had to die at that age. I lost my only brother when he was 15, and both my parents at a reasonably early age too. So I don't know why these things happen the way they do: they just do. Some things are just too hard to figure, and it doesn't matter how much thinking I do, I can't come to any answer. I find it harder to think about some of the things that happened to her; like one time she had to have an epidural and she ended up with 8 needle holes along her back. Those kinds of things drove me to screaming point. The huge issues I can let go, but some of those smaller things were sometimes more difficult. "

For other parents a religious faith isn't as important as a strong sense of a spiritual presence in what has happened, in spite of their personal pain.

"I've always had a deep faith and sense that we're all part of something which is much greater than ourselves and that I don't have control. So in a sense that made it easier for me to find acceptance. I can remember a time when things weren't looking so good when our daughter was not really recovering in the way that she should have been, a moment when I just thought, 'I've got to give this over.' Not give up, but give it over and not try and keep control of it because I realised that you can't. When you do give it over, whatever the outcome, you can live with it. When I say 'give it over,' I mean if people didn't want to give it over to God, it can be thinking of it as giving it over to the inevitable; let it take its course, because otherwise you can end up in that place where you're bitter and blaming and full of remorse about what you didn't do."

"Your faith changes too. You just can't believe that your child died and that's it. You just believe that there must be something else. So my Christian faith has changed. I go to church occasionally. I'd like to get there and do that more often, and I enjoy it when I do. But I do think my faith became stronger."

"In a way, I've found that his passing has been an incredible gift, although I miss his physicality enormously and life is always tinged with that deep sorrow. It's the difference between living on a human level and living on a spiritual level. On a human level it's really hard, because you're constantly reminded of the loss. But on a spiritual level, now I'm feeling more and more the enormous gift of him being alive in spirit, and what that means in terms of my life. If he were here on earth, he would be off with his mates, down at the pub or off with the girls, and Mum would just be over there somewhere! What I've learned to do is acknowledge the spiritual gift but on a human level I carry the sorrow, a little bit like a cloak. Sometimes it overwhelms me, but most of the time it just sits there. When it does, I just go with it. It hits you from out of nowhere at the craziest times when you least expect it. That's the hard part. You can't protect yourself from that; it's just the way it is."



For some parents, the death of their child gives them spiritual experiences that surprise them

"It was funny when he died; the sun shone through a crack in the curtains and shone on his face. It was amazing because I closed my eyes for an instant and I saw this sunbeam and my dad was there waiting for him, and he took his hand and said "Come on. It's alright. I'll look after you." It was funny because I wasn't really close to my father and that really shook me because I thought of all the people I probably actually wouldn't have chosen Dad to be there, and yet I saw it so clearly. And I just thought that there really is something else out there."



"I do feel his presence with me still."

"When he died it was an incredible experience for all of us because we could actually feel his spirit rushing through us. And afterwards he would let us know he was around by lots of little things that he did. He would do things: like he would wake me at the moment of his death which was five past three in the morning, normally by turning on the stereo. Other times I would wake up at that same time to the smell of toast and go downstairs thinking my daughter was up, but there was no one there. One time we were all sitting in his bedroom and he just shot all the CD's out into the middle of the room. Those things were a real comfort. There's not a lot of people you can share those things with; a lot of people think you're off the planet. They're really scared or they're too cynical to take it on board. I'm careful who I share that with, but in another way I don't actually care about their judgements now. "



Dealing with other people's responses

Te mahi ki ngā whakautu ā etahi atu tangata

One of the big issues bereaved parents struggle with is how to deal with other people's responses to their child's death. Sometimes they are surprised and hurt by the responses of people they hoped would support them.

"People were funny; I remember one day I was in the supermarket and a girl saw me and she quickly turned and went the other way. I'd read that often, how people do that and things like crossing the street to avoid you, and it actually happens! They didn't know how to deal with it. My brother was a classic; he never came to the funeral! He came out to stay some years later and we spent some time and started talking, so I asked him why he didn't come, and he said, 'I couldn't deal with it.' There were all those things that went with it as well that were hard. I found it very hard to deal with my mother, because she was grieving so much. I remember her saying, 'It should have been me,' and that was hard. I found it very hard to deal with her grief. We had a fall-out a little bit – we mended it but I think it was just that the grief was so much that neither of us could cope with it. I mean, I always thought my mother would be there for me, but she couldn't handle it either!"

Parents often find themselves in the position of being the supportive one for other people who are very upset about the death.

"Another thing I found really hard after he died was when people either emailed or rung up and they were obviously grieving and I felt like I had to carry their grief as well as my own and I found that really hard. I felt like I didn't need that. They didn't understand at all. It was really hard having to field those phone calls. People would be bawling their eyes out and I'd spend my time comforting them! I understand that people can't see it when they haven't been through it themselves; I mean I'm sure I was like that before."

Most bereaved parents have a horror story about people who don't know how to respond, or respond in ways that are at best unhelpful, or maybe just downright rude.

"Haven't you moved on yet?"

"I understand"

"I know exactly how you feel"

"I actually lost a friend, as in a friendship, because this girl turned round to me one day and she said, 'For goodness' sake, you've got another child! Don't you think it's time to get over it?' This was a girl that I'd grown up with! I was just devastated. I just could not believe that she'd said that to me. I thought, 'Oh my God, you callous cow!' That was the end of that friendship. I was devastated all over again."

"I felt like I carried a lot of people through that time in the months after she died. And I don't know whether that's good or bad. I carried people who couldn't deal with what they were going to say and so you were trying really hard to make it OK. You don't like seeing people deliberately cross the road, but you do! There are some really dumb things to say, and people say them."

"You have to realise that everyone's doing the best they can. And when someone comes and says, 'I know exactly how you feel, my cat died last week' you feel like hitting them in the face, but you know, that's their reality, and it is as bad."

"Other people's responses were very difficult to deal with. Very much so. It was a sensitive situation because I didn't want to hurt them and sort of tell them off and so most of the time I just had to swallow it and accept that there's no way that they could understand it from my point of view."

The cultural background they grew up in can make a big difference to the way people go about grieving for the death of their child. As well, families have their own traditions and ways of doing things. Problems come up sometimes when the ways of the extended family are different or more traditional than the bereaved parents.

"Both of us are of a Chinese background and we noticed that made a difference in the grandparents and their reactions. With Chinese people, often the first-born child, particularly if it's male, is the most important. I never thought my parents would place a lot of importance on that because they've never followed strict Chinese culture with a lot of things, but after our son died they totally put him on a pedestal. Especially my mother. It was like she couldn't recall anything negative. It was basically like he was always the perfect child: he was never naughty, he never did anything bad and these other two grandchildren just don't measure up! 'How come they can't be like him?' and all sorts of carry-on. It wasn't easy. I felt terrible for my other two children! It probably wasn't until I had the baby this year that all of a sudden there's no more mention of that pedestal business. The baby's the new focus for them as well."

"We had her cremated and we still have her here because we can't make up our minds about where she's going to be. My husband's Māori, but he's a bit estranged from his family and when she died, we talked about it and decided to have her cremated. I didn't realise it was going to be a big thing until afterwards when his family let us know that they weren't happy about that, but they did eventually accept the fact."

In spite of the unhelpful responses, parents also find that other people's responses can be a lifesaver at times.

"The gestures that people make are really quite astounding, and they are all building blocks that get you through that difficult time, and to next stage, and the next stage, and the next stage. The thing I would say to anybody in the support network is, 'Keep it going.' I can remember times when I would be feeling pretty low, and someone would ring up. As if they just knew! They would just ring up out of the blue."

"The good heartedness of people – all that support in whatever way it's given really, really helps. You do really remember small things about people's generosity. I think that means a lot. It all adds up. One thing that really stands out in my mind for instance is this friend of ours who really doesn't like cooking and made us this dish and left it on the doorstep, and honestly, it was such a labour of love! It brought a smile to my lips because I thought, 'Here is a person who hates to cook, and yet has done this thing!' It means a huge amount. We were always so aware of the generosity of people, all the time. People would come who hated going to hospitals, people would come who obviously found the surroundings distasteful to them – you know how dreadful those waiting rooms and community spaces can be – and people just showed such tremendous generosity in coming."



What about your other children?

Mē pēhea etahi atu tamariki?

One of the big worries that bereaved parents have, if they have other children, is how the death of their sibling is going to affect them. Like adults, children and teenagers handle bereavement as individuals and have very different responses. It is particularly hard to see your living child struggling with the same kind of pain that you have.

"My daughter was in her 7th form year of school when he died. She became anorexic and very reclusive. She felt enormous guilt because her tissue type didn't match his on any count, which meant that she couldn't give him the bone marrow transplant. They were really close as siblings and she just turned in on herself. She poured her energy in on her work, didn't eat, became very thin and reclusive and depressed. Suicidal. She was doing Bursary Art at school, and she dedicated one of her projects to him. It was a print project so she actually did her portfolio on the progression of the disease in lithographs, taking it through from when he relapsed right through to his death. I think it probably helped her to express some of her pain. That was the way she coped. She holed herself up in her room and used his room as a studio and worked like a dog. She ended up getting the top marks for the course, but at a personal cost. But in a way it was good because at least it was a focus. It was horrible as a mother; it was a nightmare seeing her in such a terrible place and there was nothing I could do."

Another issue is a sense of guilt that many bereaved parents feel about their children. They are often aware that preoccupation with their sick child or with their own pain has meant they have not been there for their other children as they wish they had.

"His brother was nine when our son died. He really had no idea, he really didn't. I can remember, he was quite the joker and he was always clowning around trying to make everybody laugh. I got him one day in the hospital and I shook him and said, 'Your brother is going to die, don't you understand that?' I was angry with him because he seemed to be trying to make jokes and be happy. But it was just his way. I can see that now. I look back and say, 'Ohhh. The mistakes you make.' It's hard. I see it in his eyes. It still hurts him, but he doesn't talk about it the way I do because they don't know to do that."

"I felt really guilty because my younger son was born a few months after she was diagnosed. She was in hospital after Christmas and I had this young baby and I was breastfeeding him and with all the shock of the diagnosis and spending so much time in the hospital my milk dried up. I was mortified but in another way I was glad because I couldn't care for both of them. My mother cared for him then. And then the year she was having chemotherapy I spent most of the time in hospital with her and he was with my mum and dad again. And then when I was caring for her here at home, we actually sent the boys away again as well. He was three by then, and I made the choice to send them there and to just care for her because we were sleeping in the lounge with her, and she couldn't stand light or noise or the different smells of cooking. I was mortified to think that I'd had this son who I hadn't connected with so much because I'd done so much for my sick daughter."

"The kids are probably the ones that suffered the most, because when our daughter was sick they were palmed out to grandparents. We've lost some pretty important times, because we just had to concentrate on one child. But they grew up fast, and I don't think it did them any harm. They had to, and they came to grips with stuff and they've learned from it and are doing really well. They've had counselling, and that helped too."

Some parents make an effort to make up to their other children for the ways the illness and death is affecting them.

"In that first year after she died, I didn't change anything. I still had all the things around me. But I was very aware that I had to do things to make sure my other children didn't suffer. I remember saying to my kids, 'Look, Mum and Dad feel sad all the time, and you might feel sad, or you might not, but you shouldn't have to feel sad because you're little boys. You should be worried about little boy things; what goes on at school and friends and things. You have got to let Mum and Dad do things as a Mum and Dad.' I guess after trying to work through that I determined that I would try and make it up for them somehow. I did things like I made a point of packing all her things away in boxes and putting them in cupboards. It wasn't till I did that, and then went back to work that things started to get better."

There are many good books about children's and teenagers' grief that can help parents to deal with their children. Often information can make a big difference to your confidence that you are doing all that can be done to support them (see "Useful contacts and information" on P. 41)

Information is important for your children too. It's important to remember that children pick up as much or more from our body language, as they do from what we say. It can be confusing or frightening for them if they see from your face and actions that you are distressed, especially if they don't feel that the death is something that can be talked about honestly and openly.

"I had worried a lot in the two years when our son was terminal about how it was going to affect his brothers, and I actually went to a talk by an American psychologist speaking about talking to children about illness and death. I found it very useful. The basic message I got was that you don't need to tell them a lot about it unless they hint to you or they ask you, so that's as far as I left it, but I did put in an odd word towards the end to tell them that he was getting sicker and sicker. And then when he died, the two boys just seemed very matter of fact about it. We're Catholic, and I think having some sort of spiritual belief helped to explain it to the children. We talked about heaven and what happens to people when they die, and it made it easier to explain it to them. They coped well; I had expected their behaviour to go backwards like all the books say but none of that happened and I think perhaps it was because we kept the channels open about talking about him."

Creating an atmosphere where things can be discussed easily means you will be more aware of how your children are coping with their feelings about it all.



One issue that parents find hard some time after the death is finding ways to deal with later children who can't remember or never knew their sibling who has died.

"I think it's been quite hard for our daughter to have this awareness of a sister she didn't know. The photos and all the things that she got that were her sister's special things. She used to talk about it quite a lot when she was small; how she'd love to see her. I think she kind of thought that maybe she would! She was always very keen to tell people that she'd had a sister, which I think is really nice."

"Unfortunately, our little kids cause a whole new set of problems relating to our daughter. Of course because they weren't born it's hard to keep her alive for them. I find myself getting a little bit crabby when they don't acknowledge her as their sister. I can understand why though. In our family it's only me and my husband who remember her. It's very hard for us to celebrate things like birthdays because they just don't get it. And they have interesting questions. The little one talks about wanting to go to the 'gravy' (that's what she calls the grave) and when she's there she says, 'Course she's a butterfly, but how can she be a butterfly when she's in the gravy?' And then the older one starts talking about 'souls' and it just goes on and on. It gets very tricky to know what the balance is for them; to get a good balance without overkill. And it's going to continue to be tricky until they get older and get a better sense of it. I think they have a far better idea about death than most children. But I don't think it will ever be something that they can really get a sense of."



What about your other children?

Mē pēhea etahi atu tamariki?

When parents have a chance to look back some time after the death of their child, they are often able to see that they have developed parts of themselves that were not there before, and that they value in themselves.

"I think I am a completely different person. There was a certain superficiality about our lives before. I don't think I was a particularly mature person: I hadn't had a huge life experience before, and it adds hugely to that. It helps you to reach out to other people in a way that you haven't been able to before. I am more empathetic, and I have better resources. It's all those things about not being afraid to reach out to people when something happens; this has given me much greater confidence, and much greater maturity. I notice that my parents, as time goes on, have such great wisdom, and much of it is around looking after people, and having experiences of what happens to people in their lives; it's a richness of experience that gives them that wisdom."

"It's made me look at people's situations and not prejudge people, and just knowing that people are so different, and what they do is different, and what I do and what someone else does is quite different, but it doesn't mean that one is right and one is wrong. So I think my view on people has changed and that I try not to prejudge and understand that they have to do what's right for them."

"I've grown through this. I know that I've got very good at dealing with problems. I try to think things through now. My husband suffers from anxiety and panic attacks, so I try to keep things calm and think things through. Don't get me wrong; I'm not a saint! But I'm pretty good at listening to other people. And as a teacher I've noticed I'm very good at picking out children who have problems. I'm quite happy to talk to parents and can relate to them well. I think I'm more empathetic now. I know what it's like to worry about your children. It's made me a better teacher."

Many parents reflect that the illness and death of their child has changed their priorities.

"I've thought a lot more about what's important in life, and about enjoying things and trying to do them now or making a time to do things rather than 'one day, we might do that.' It's changed my priorities."

"I think that in those two years that we had with him before he died, we didn't know when or how long he was going to be with us, so we just treasured every day and we made sure that we did as many special things as we could together. We just grabbed a bit of joy out of every day. I think after he died, we've tried to maintain the sense that we shouldn't plan too far ahead; live one day at a time. And if the children get a chance to do something we encourage them to grab it now because we don't know when that opportunity will come again. In fact, it's also affected the way we think about their futures. I haven't been thinking, 'I wonder what they'll do with when they grow up?' I just appreciate them for what they are now and who knows what they'll be when they grow up, but that doesn't matter. It's a positive thing: I think before our son was terminal, we spent a lot of our time thinking about what we'd be doing five years from now, but then when he became ill those kinds of ideas were so redundant."

"I've always been a believer that you do what you feel is right for you at the time. It doesn't matter what people think. And now, going through all this, it gave me the excuse to do that. So if people said to me, 'Are you having a bad day?' I'd say, 'Yeah, I've just lost my daughter, so shut up!' And while that's a bit tough, I'm a lot more honest with myself. I'm certainly not as patient as I used to be now. I try to find the positive in that, and I think I've got a handle on it: you worry about the important stuff and to hell with the stuff that isn't."

Parents often comment that their attitude to death has changed a lot.

"Death doesn't scare me anymore. Cancer doesn't frighten me anymore. Because I think everything happens for a reason. If it's going to happen, you're going to learn from it and whatever happens in the end is just part of your challenge in life. Before my daughter died, I hadn't even thought about why we are here or any of that sort of thing. I'm not particularly religious. I used to just think that when you died that was it. Now... no it can't possibly be like that."

Most parents look back on their time with their child and reflect that, though it brought them great pain, it's something they don't regret.

"It definitely changes you. It makes you a different person; I wouldn't say it makes you a better person. The privilege of having her as a daughter has been amazing and I would not have changed that. I mean I would have loved to have changed the outcome, but I wouldn't have changed that time with her."

"In the middle of the sadness we're always aware of the legacy our daughter left; her fierce strength, her courage and love, and the fact that right to the end she was always concerned for others."



Advice from parents who've been there

Tohutohu mai i ngā mātua kua tae mai ki reira

The parents whose stories are in this book had some suggestions to share with parents 'new to the club'.

"You can get back to a normal life afterwards. Things get easier with time, but it's going to be different for everybody so you can't compare yourself with anybody else who's been through the same thing: everybody experiences it in different ways."

"The main thing is to take your time and do what you need to do. What works for one person isn't right for someone else. You have to find whatever is right for you and not for other people, and not feel guilty for doing that. You have to find out how it suits you and your family."

"What I'd want to say to other parents is that there are no short cuts. I've found you do have to go through it. We can talk and laugh about her and what a feisty stropky number she could be and yet what an absolutely loving person she was most of the time, and yet other times, I'm just overwhelmed by sadness that she's not here."

"Follow your heart. You must do what you feel. It's never going to be wrong. Forget about everybody else because it's your one chance to do this for your child. You so look for other people's advice. You really want someone to give you a handbook and say 'right, you must do this or that.' You look for that sort of thing. It's such a heck of a shock that you don't know what to do. Do what you think is right for you and don't worry about what anybody else thinks. I do that now for myself and for my other kids too. And just know that it will get better but it's going to take a long time. And there's certainly no time limit."

"I think people need to take care of themselves when this happens and allow themselves time. I think the time is the crucial thing. There is a tendency to rush back in, and then you can feel deeply confused because life is just rushing on and it's like you're not acknowledging what has happened. So it's important to take real time around the whole process of coming to terms with what has happened. I remember one of my sisters came from Australia when our daughter died, and the other one came down from Taranaki. She was in a senior position in a secondary school, and she said her last words to her principal were, 'I don't know when I'll be back!' The open endedness of that gesture: these are the things that you never forget! And we did take the time. The three of us particularly took the time to just be around together. It was just fantastic."

"My advice to newly bereaved parents would be to be as honest as they can with their feelings and to actually allow themselves to have them for as long as they need to, in spite of what anybody says to you. Do what you have to do. And if that means going crazy, let yourself go crazy. If that means crying for two years, cry for two years. If that means going to bed for two years, go to bed for two years. Just truly go into the experience."

"I think it's a day-to-day thing. You just wake up each day and some days are really bad and other days are fine. You've got to think, 'Well, tomorrow could be better.' You get through the day and look after yourself. There's a lot of people out there who want to give you advice, and tell you what would be best for you, but I think you've just got to work through it yourself and do stuff at your own pace, and how it works for you. You can't run away from it; it doesn't go away so you have to just deal with it on a day-to-day way."

Useful contacts and information

Hoapā whai mua me ngā kōrero

Child Cancer Foundation

Child Cancer Foundation is there to support you along this journey and can help in many different ways. In addition to the day-to-day support provided by your family support coordinator, you can take part in specialised programmes and support throughout the year. These are focused on finding ways to go on living without your child, while cherishing their memory.

Child Cancer Foundation also hosts Remembrance Days around the country each year, which will give you an opportunity to honour and remember your child alongside other bereaved families.

If you would like to know more about how Child Cancer Foundation can support you, please get in touch with your family support coordinator or the national support office:

P: 0800 424 453 | 09 366 1270

E: info@childcancer.org.nz



Grief Resources

Kenzie's Gift

www.kenziesgift.com

Kenzie's Gift is a NZ charity organisation supporting the mental health of tamariki/ children and mātātahi/ young people affected by serious illness or grief within the whānau. They do this by providing one-on-one therapy, serious illness and grief kits and extensive online resources.

Skylight

www.skylight.org.nz

Skylight is a NZ organisation that supports grieving children, young people and their families. They provide a hub of online resources with articles, videos, links, an online shop and a physical hub offering personalised information, support, counselling services and a library for nationwide loan. Contact Resource Centre staff on 0800 299 100 or 04 939 6767.

Redkite – Australia

www.redkite.org.au

Redkite is an Australian organisation supporting families facing childhood cancer. They have an extensive collection of online resources that are regularly updated in providing information to families navigating different challenges, including bereavement.

The Grief Centre

www.griefcentre.org.nz

The Grief Centre is an Auckland-based service designed to offer loss and grief support to youth, adults, families or whānau experiencing any form of significant loss.

They also provide community talks and events for bereavement support and aim to ensure that everyone receives support that is useful to them by making counselling affordable and free downloadable resources readily available.

The Dougy Centre

www.dougy.org

A US-based organisation whose mission is to provide grief support for the whole family. Whether you're grieving or helping someone who is grieving, the Dougy Centre has developed a wide range of resources for people of all ages who are grieving, before and after a death. Find help you can access anytime – tip sheets, activities, podcasts, and more through their personalised toolkits.

Grief Encounter – UK

www.griefencounter.org.uk

Grief Encounter is a UK charity established to support bereaved children and young people and help families find hope and healing after the death of a loved one. Grieving is unique for everyone, and the organisation have produced a range of Grief Guides to help people navigate their grief, covering all kinds of subjects that are often hard to comprehend at difficult times.



Paediatric Palliative Care – Australia
www.paediatricpalliativecare.org.au

This new website will continue to evolve over time and is a one-stop destination for quality paediatric palliative care information and resources for families/ carers, young people and health professionals experiencing paediatric palliative care. Paediatric palliative care is about improving the quality of life of infants, children and young people diagnosed with a life-limiting condition and supporting those who care for them.

This new website reflects the diversity of those experiencing paediatric palliative care and the resources on this website are designed to support families to access quality information as they care for their loved one.

Memory Sites

Tributes Online www.tributes.co.nz

Tributes Online is a safe, secure website where funeral notices, a photo, personal comments and family history or eulogies can be placed as a memorial to the person who has died. Photo presentations and livestream links can be uploaded for 60 days to pages created by funeral homes.

All funeral homes are able to have immediate access to this website and can create tribute pages for you, or if you prefer you can register to create a tribute page with tribute book yourself.

Winston's Wish
www.winstonswish.org

Winston's Wish is a UK charity that helps children, teenagers and young adults find their feet when their worlds are turned upside down by grief.

They offer a range of helpful and practical resources, information and specialist publications for families and professionals supporting grieving children. The range of content on topics includes videos, blogs, books, talks and workshops that help young people explore their grief. There's also a variety of activities, reading lists and extensive publications to explore to help the child or young person being supported.

Webhealing.com www.webhealing.com

An interactive website established by Tom Golden, an American grief counsellor and writer who specialises in working with men. His website offers parents opportunities to read other parents' stories, as well as articles and videos about grief.

Books

There is a huge range of books about grief for adults, young people and children.

Talk to your family support coordinator or a librarian about what is available that will suit your particular needs.



He Whakatauaki: Proverb

Whāia ko te mātauranga hei
whītiki te iwi kia toa ai

Seek ye from the fountain of
knowledge so the people may be
uplifted, thrive, and prosper





Contact us

National Support Office


76 Grafton Rd, Grafton,
Auckland 1010


Phone 0800 4 CHILD (0800 424 453)


Email info@childcancer.org.nz

Website childcancer.org.nz

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 [Child Cancer Foundation](https://www.linkedin.com/company/ChildCancerFoundation)

 [Child Cancer Foundation](https://www.youtube.com/ChildCancerFoundation)