

The following are a collection of intensely personal accounts of the experiences of a number of parents of children with disabilities regarding grief and loss. They have been collected by Novita Psychologists in the course of their work with parents and also from a number of videotapes. (see [Resources referred to in this document](#))

Statements are grouped under headings associated with typical feelings associated with grief and loss.

SHOCK

"Well, to tell you the truth, I felt actually quite sick when I first heard . I mean, ... to get told that your child is disabled and has got cerebral palsy is quite upsetting."
Tony (father) from the video 'You're Not Alone'.

"I'll never forget when, um, our child had had a really long seizure and been take to ICU, Intensive Care, and when we got home from that visit and she'd come off the incubator and, you know, she was OK but we really didn't know what was going on. Um, I'll never forget sitting on the front seat, of our, of our house, just looking out feeling completely lost, tears running down my face and my husband was out doing, moving the lawns and all I could keep thinking was, life has ceased to exist as I, as I know it, my marriage is in shatters, my husband doesn't care. And in fact, he was coping with it in the way he needed to cope, he needed to get away, he needed to do something in order to think, but at the time I couldn't really appreciate that."
A mother with a child, 'Sally' who is registered with Novita from the transcript of the video 'A Mum's View' made by a Novita psychologist for a Dads Group presentation.

DENIAL

"... You sort of think, 'Well, hang on, she doesn't look disabled to me!' you know. 'They must have got it wrong, there's something wrong' you know, so you tend to go through all sorts of denial . Straight away, I don't know why, maybe it's a natural reaction, you think 'Well, they'll find a cure for that sort of thing.'"
Tony (father) from the video 'You're Not Alone'.

"Particularly in the early stages after diagnosis, you are desperate for a cure. You're desperate for that magic cure, magic wand, key, whatever. Something that's going to unlock your child's potential, that's going to cure them. ...You know you can do that for years, and I think many of us do that for years."
Sue (mother) - from the video 'It's a Long Road'.

"I didn't want to think that my child would be disabled. I just didn't want to accept that. You just don't think it can happen to you and it does happen to you and that's a real weight on your shoulders when it does happen to a family. ...None of my friends have got disabled children and I've seen many disabled children out there and I know there are huge problems having a disabled child and you start thinking of all the problems associated with it. ... To me as a male it did take a long time for it to sink in

and I can recall the day it actually sank in I was driving along the west coast highway and I had all these guilt feelings come through and I said 'Why me? Why is it happening to me and my family? What's going to happen to us as a family? How are we going to cope with this?'..."

"It was very emotional ... I just pulled up in a car park and started, all these things started going through my brain."

"And I was going to speak to my wife about it, ... but once I'd sort of got through it after about fifteen minutes, I decided I wasn't going to mention it to her because you know it's just a very emotional period, and I didn't want her to think that I wasn't going to, I couldn't cope with the situation."

"I've never told anybody about that situation. I honestly couldn't speak to someone else about it. It's very hard for a man to speak about emotional situations like that, you know, and as I said, I could have spoke to my wife about it but I never have, she doesn't know."

Richard (father) from the video 'Going The Distance'.

"So you try to keep your spirits high and always look for the best, but inside I thought 'Wooh!, you know, umm, this could be really bad.' ... I think I lied to myself to a degree saying 'I'm sure that they'll sort something out and we'll be able to, with the help of the doctors, and medicine's so good, that things will come right.'"

Gino (father) – from the video 'Going The Distance'

"Denial is a normal, healthy process of being able to cope with, or not hearing news that is too hard to cope within the initial stages. It can be a time of looking for alternative treatments or some way of being able to change what is the news about my child. It can also be a time of gathering up inner resources, to actually become ready to hear the news that my child will never be normal as society defines normality."

Tony (Counsellor) - from the video 'It's a Long Road'

ANGER

"There was like a frustration, um, where I could almost be angry with him for not being normal. Which is, which is a dreadful thing to say, but It's also a very real emotion, you know. You almost, like you want to pick them up and say 'why can't you do this?'"

Sue (mother) - from the video 'It's a Long Road'.

"Anger's a natural response to a distressing situation, it's really the body saying 'I don't want to be here, I don't what this to be happening to me', and people need permission to express their anger and to feel their anger. People can be, want to say 'Why me? or Why us?, How did this happen?, Who is to blame?' and they may look for people to blame, 'Why did God allow this to happen?'. A lot of questions like that are raised during the emotion of anger. For some people, it can be threatening if a person starts to blame God or gets angry at God, but really God is big enough, and cares enough and is loving enough not to need protecting at those times. Anger can also help us see the shortcomings in those people around us. And sometimes anger can be directed to those nearest to us, our partner who we hoped would understand exactly what we needed but seems not to. Also other family members can feel the brunt of a person's anger. ... Anger can have a positive aspect, in that it can be the

motivating force to say 'I am not prepared to be here any longer, I'm going to find another service or something that will make a difference for my child or I'm going to move on from where I am at the moment'. So it can be positive, not just negative."
Tony (counsellor) - from the video 'It's a Long Road'.

GUILT

"It was very difficult for me, because I couldn't handle the anger that I felt, that I couldn't make this child better, that I couldn't stop him crying and I couldn't... I felt very guilty, very guilty, because he was this little innocent child that had never done anything wrong, and it wasn't his fault that he couldn't do what he was supposed to, he was just a baby and I felt very guilty, very guilty."
Paula (mother) - from the video 'It's a Long Road'.

SCARY OR MORBID THOUGHTS

"And it was only when I went to my first Kalparen mothers' camp that I was sitting down with a group of women, we went to have a coffee, it was at Pinjara, and there was a lady talking about her child. And she, her child had Down Syndrome, and she was recounting how she would stand at the doorway at night and watch him breathing, and pray that he would stop... And that was the most liberating moment for me because I realised that someone else felt the same way as me and that I wasn't alone. And um, maybe I wasn't such a terrible person, maybe it was normal to feel that way and I came home and I just, I felt so empowered by that."
Noreen (mother) - from the video 'It's a Long Road'.

FEAR

"... I was going to, potentially have to give up my career, I was going to have to look after this disabled child. I was going to have to face the world, you know, every day with this child who was different. And the physical side of that, and also being a nurse and having some knowledge of disability, I was fearful of the unknown, but I was making the unknown up in my head as I was going, just like anyone who has an image of child in a wheelchair or, you know, we didn't know if 'Sally' would be in a wheelchair at the time or not. ..."
A mother with a child, 'Sally', Novita client - from the transcript of the video 'A Mum's View' for a Dads Group presentation.

BARGAINING

"Once I got over the initial shock, I went heavily into denial and I just thought if I, if I prayed enough, I bargained with God, if I was good enough, God would make him well. If I worked hard enough, if I did enough physio with him, you know, he'd come good and that was a real pressure to work with that, to be, you know, every day feeling that his becoming normal depended on my input."
Noreen (mother) from the video 'It's a Long Road'.

DESPAIR

"And I became very despairing that it would ever be different. I couldn't, I couldn't see a day when it would ever be different. I just couldn't see the light at the end of the

tunnel. And I remember being in such pain about this, about having lost all my dreams and my hopes and I remember just wanting to talk to someone who would know what it was like, who had been through it, and who could tell me that I wasn't going to feel like this forever. And I remember sitting down, looking through the yellow pages, just looking for someone, and never finding anyone."

Noreen (mother) - from the video 'It's a Long Road'.

ISOLATION

"There were very few people I could keep in contact with, primarily because my day was divided in to an hour and a half or two hour slots. ... I felt tremendously isolated. I, if I had had an antenna and a green face, I could not have felt more isolated. ... I often, just, so longed for somebody else to come up and start talking to me, that it became almost like this gnawing ache inside me that I was so different, not only did I have a child that was different, I was so different from regular mums. I didn't do the stuff they did".

Kate (mother) - from the video 'It's a Long Road'.

"I think that living in the country with a disabled child is a bit of a two-edged sword. On the one hand, you're better off in some ways because everybody knows your child. On the other hand, it can also be very difficult, and I found it very difficult in the aspect of the fact that you are isolated from services. It's harder to access counselling, it's harder to get in contact with other mothers who are going through the same thing. And that contact with other mothers is so vital, because that's where you find out that what you're going through is quite normal. ... I have found out recently that you can actually have phone counselling, from anywhere within the state."

Noreen (mother) - from the video 'It's a Long Road'.

LOSS OF CONTROL/PUTTING UP A FRONT OF CONTROL

"I just couldn't get out of bed in the morning. I would basically spend all day in my pyjamas. ... I think a lot of the reason I felt so bad was like I was trying to hide how I felt. I was trying to sort of act so normal and in control and capable and I wasn't. And you can only keep that up for so long before you fall in a heap."

Paula (mother) - from the video 'It's a Long Road'.

PROBLEMS WITH MEMORY

"I just became more and more anxious, and more and more depressed and I didn't feel like I was good enough for anybody. ... I had trouble at the time remembering anything if it wasn't written down because my life was so full and so complicated."

Kate (mother) - from the video 'It's a Long Road'.

WHY ME? WHY US? WHY MY CHILD?

"Ah, my two boys, Jack and Harry are 14 and 9. They both have a condition called Fragile X Syndrome, and our daughter still has some risks of being affected. Jack is very mildly affected. We were convinced that Harry was fine, because he has a very different personality. When I was told that Harry was also affected, um yeah, the bottom fell out of my world. And I did have 'Why me? What have I done to deserve this, what did I do?' You know, there was sort of, in my mind, '... well, any family can

cope with one, why have I got to cope with two?"
Sue (mother) - from the video 'It's a Long Road'.

LOSS OF BALANCED PERSPECTIVE

"Jason was the centre of my universe. ... I had no balance in my life, so when someone would say something to me about Jason, it would devastate me. ... If you expect understanding, as I did, I just set my self up for hurt, because it is a very difficult thing to understand unless you live it."

Noreen (mother) - from the video 'It's a Long Road'.

THOUGHTS

"One of the great workshops at camp is journaling. And with journaling, you write down your thoughts and feelings on paper. And it's actually very powerful because it puts down how you're feeling, and it gives you space to look at it from another perspective. And quite often things seem a lot larger in your mind than they actually are. And you put it down on paper, and it puts it in the right perspective."

Noreen (mother) - from the video 'It's a Long Road'.

"To me as a male it did take a long time for it to sink in and I can recall the day it actually sank in I was driving along the west coast highway and I had all these guilt feelings come through and I said 'Why me? Why is it happening to me and my family? What's going to happen to us as a family? How are we going to cope with this?', ... It was very emotional ... I just pulled up in a car park and started, all these things started going through my brain."

Richard (father) from the video 'Going The Distance'

CRYING

"And I was seeing children her age and the difference was obvious, difference physically and intellectually was obvious and that you can't, you can't hide that, you know, it is like that and the grieving and like the other thing that happened as a result of that was I would see people with two daughters about the same age as our children, with about a two year gap and I would be looking at them and I used to walk home from kindy and playgroup at times in tears, because it was just too hard seeing what should have been for us and seeing other people enjoying that and taking it for granted and I felt like, you know, at times saying to people you know 'cherish this because you are so lucky'... you've got to remember everyone in the family, including grandparents and friends are grieving and that was one of the other things I found very difficult, was having to help other people through their grieving, and I'll never forget one day having coffee with someone, Sally had a seizure, and I am there administering, you know seizure management, I'm doing Rectal Valium, I am trying to keep calm and in control, look after my other daughter, and this mum burst into tears, and I can remember just looking at her and looking at her and thinking 'no, I can't deal with that, I have enough here. That is your problem, I'll see you later'. I didn't say it and it didn't mean the end of our friendship but I thought at that time, 'I can't cope with that', 'I am going to stick with this and we'll sort that out later' and so yeah, that sort of thing."

A mother with a child, 'Sally', Novita client - from the transcript of the video 'A Mum's View' for a Dads Group presentation.

FRIENDS – NEW FRIENDS OR OLD FRIENDS?

"My friends have been wonderful, I have lost a few, a couple of friends I suspect through Sally's problems, whether it was the way I was reacting to the problems or Sally's problems per se, what ever I think a couple of friendships have gone by the way side, but on the upside I made some new ones, which has been um part of, you know, the ebb and flow of friendships. But that's been great, because they have been a great support, and some of them have offered to have Sally for a sleep-over, um, and I think you need to get your confidences and if someone offers, take them up on it, don't feel like you need to protect them, they are offering because they want to be, want to be friends and don't be afraid to take that ..."

A mother with a child, 'Sally', Novita client - from the transcript of the video 'A Mum's View' for a Dads Group presentation.

WITHDRAWAL

"I was trying to carry on working as normal, trying to keep, sort of, life as normal as possible. And I suppose that's also a bit of an escape because you can go out to work ... and things seem fairly normal when you're away from home, whereas, if you're at home with someone who's sick, it's there confronting you all the time."

Gino (father) from the video 'Going The Distance'

ACCEPTING

"For as long as we've got her, ... this is how I look at the quality of her life. I take a day at a time, and what she's going to do is what she's going to do. She's probably going to have a pretty good life because we love her heaps!"

Lesley (mother) from the video 'You're Not Alone'

"I finally learnt to disassociate the disability from the beautiful human spirit, and in doing that, you know, that's freed me a lot to love Jason. And I think also, until you come to that point where you accept that this is who he is, and accept him for who he is, you are fighting against it the whole time. And it's very hard to love completely, until you completely accept the individual that you have."

Noreen (mother) - from the video 'It's a Long Road'

RESOURCES REFERRED TO IN THIS DOCUMENT

The following resources are available from the Novita Toy and Resource Centre (Phone: 8243 8316) Email: library@novita.org.au

- A Mum's View – Interview of mother of Novita client (videotape)
- Going The Distance – Interviews with three fathers of children with disability (videotape)
- It's A Long Road – Interviews of four mothers of children with disability (videotape)
- You're Not Alone – Parents of Novita clients (videotape)

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