

CAN'T COPE

In all of

***Does NZDSA
welcome only
people who
are coping
well and
whose
children
are high
achievers?***

The articles on this page are from Canada and New South Wales and are used with kind permission of the authors. Issues raised and questions posed are just as relevant to us in New Zealand.

They're about problems people have in sharing what their lives are really like, particularly if they're having problems coping or if their children are not high achievers.

Overleaf two NZDSA members tell of their problems coping.

Let us know if you have had difficulties like these and how we can make sure NZDSA truly welcomes anyone whose life has been changed by Down syndrome.

Our son Richard is 23 years old and has Down syndrome. I would describe him as an incredibly compassionate person who is very attuned to the needs of others. He has a great sense of humour and loves to play an occasional practical joke. Others would describe him as a person who has Down syndrome, autism spectrum disorder, Tourette syndrome, heart disease and significant behavioural challenges. And they would be correct.

I have thoughts and

You have prompted me to write about some experiences which I imagined I would never pluck up the courage to send.

My son Rufus has Down syndrome. He is 4 years old and charms the socks of all of us. I can see that now, but for four years I have been battling long bouts of anxiety attacks and depression which began when Rufus' Down syndrome was diagnosed.

The reason I haven't written before is because whenever I read DSA newsletters, most of the articles seemed to be from families who were coping well and could find much joy in their situations. I, on the other hand, couldn't deal with the fact that my child was disabled. I would have replaced him with a 'normal' child

these places where it should have been easy and safe to be honest, something has been lacking.

Throughout [22 years involvement in DS groups] I have felt a strong unexpressed need. In all of these places where it should have been easy and safe to be honest about Rick's needs and our struggles, but still optimistic about his future and secure in his acceptance as a valued human being, something has been lacking.

I have hesitated to address this issue, out of concern for my son (wanting to portray him accurately, yet positively and respectfully), out of concerns for the

disability movement (the need to generate positive awareness and promote high expectations) and out of concerns for others with DS, whose achievements we joyfully and genuinely celebrate.

..... When we, as individuals, as local parent support organization, and as a disability movement, arrive at the stage where we can truly celebrate the gifts of ALL people with disabilities, only then will we be "practicing what we preach". Only when we are fully accepting and

people feel a sense of belonging, no matter what their achievements by traditional measure; and only when we are truly celebrating them as valuable human beings whose gifts we treasure, will we be living up to the standard for which we advocate.

*Kathleen Marafinao, Syracuse, NY
Canadian Down Syndrome Quarterly
Newsletter, Winter 2002 (reprinted DSA
NSW Newsletter Autumn 2003)*

feelings that no mother should have to confront. But who is there that I can share this with?

like a shot if I could. I felt isolated from the real world, like I had been kicked into touch to watch life go by from the sidelines – no longer able to participate. I could find nothing to celebrate. I resented his presence. I hated days when I was looking after my two children on my own, because I felt like screaming most of the time – all I wanted to do was crawl under the covers and stay there. I felt like a defective mother, seeing all of my friends with their 'perfect' children, and I felt I had failed. I felt I was being punished for leading too happy and comfortable a life until now. I had to acknowledge that the only way I could cope with motherhood was to take an unusually high dose of anti-depressants. I didn't believe articles which said "it was hard at first, but now I wouldn't have it any other way" – I could not see myself ever getting to that way of thinking. I wanted to see somebody failing to get it right – like me!

..... The general feeling of the DSA newsletters is very positive and supportive of the so-called success stories and opportunities, and so it should be. The DSA plays a huge role in supporting families. However, perhaps it could also reach out to those who are finding it too hard, but don't feel they can admit to it. Perhaps it could give space to those families who think they are failing, space where it is okay to say you don't like your situation, where it is okay to say those things which are hard to express by guilt-ridden parents, and yes where it is okay to say you wish you could turn the clock back, reclaim your former life of 'normality'. What about a space where people can make a cry for help and not feel that they are outcasts because they have negative thoughts. Political correctness all very well but I spend most of my time being politically incorrect

about my own son! I have thoughts and feelings which no mother should have to confront. But who is there that I can share this with, without the heavyweights of guilt and shame?

..... We are not openly confronting the hard issues. We are not talking about the children who are at the other end of the achievement scale, we are not talking about the things that our children can't do and how that makes us feel, we are not acknowledging the validity of people who cannot cope. And it is surely these that most need the support that the DSA can give.

I don't think it is disrespectful to our children to "confess" to the hardships, I think it is open and honest, and can only improve our capacities and love for them.

*Harriet Gambles
DSA NSW Newsletter Winter 2003*

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*Two of our members tell with
bravery and honesty of their
problems coping*



Thomas & Matthew

Thomas and Matthew celebrate their second birthday soon.

For me it has not been an easy time. I have found the past two years a challenge in many ways. It has taken me all my inner strength to get through each day.

It was a huge surprise to find out during an early scan at seven weeks that what we thought was our third child was in fact twins. Throughout my pregnancy I continued to be amazed that I was carrying twins. But to find out within hours of their birth that both boys had Down syndrome was almost too much.

They were born at 34 weeks gestation by caesarian as Twin 1 had stopped growing and was somewhat smaller than Twin 2.

I first saw them in NICU at National Women's Hospital when they were about an hour old and immediately



Anna-Rose

I would like to introduce you to our wee poppit "Anna Rose" - who was born 12 months ago with Down syndrome. She is such a blessing and brings so much joy into our lives, that I really wonder what we did for entertainment before she was born!!!!!!!!!!

realised that Twin 1 had Down syndrome.

I mentioned this to the registrar at the time, but she was somewhat dismissive and as it was about 9.00 pm suggested I get some sleep. Neither John nor I did get much sleep that night, already concerned about our baby.

The next morning John went down to NICU for the doctors round and was there as both babies were examined by several specialists.

After looking at both boys the one of the doctors asked John if he had heard of Down syndrome and then proceeded to tell him they felt that both boys had Down syndrome and would perform blood tests to confirm this. The chromosome specialist offered to accompany John to tell me about this devastating news. I remember very little of what the specialist said but after a while I said 'so you mean both babies have Down syndrome?' and he said 'yes – I am so sorry.'

That is how what should have been a joyous time turned into something that felt so bad.

At first I did not want to go and see the babies in NICU but when my ten year old daughter suggested I come and see them with her how could I refuse? She had already spent an hour with them, helping the nurses feed them and talking to them.

Over the next few days I felt that our life was totally ruined, that we had been handed a life sentence, and there couldn't possibly be anything positive associated with having twins with Down syndrome.

The issue of the boys being identical was raised and although they did not look at all alike and had separate placentas and sacs the specialists made the assumption that they must be identical if they both had Down syndrome. It was not until some weeks later when we arranged for a private DNA test to be done that our own feelings that they were not identical were confirmed. Yes that is right – non identical twins both with Down syndrome – the odds are pretty long and yes I did buy a lotto ticket.

As the days went by and twin 1 and twin 2 became Thomas and Matthew we began to feel we wanted to get them home and begin learning about Holland rather than enjoying Italy. (see 'Welcome to Holland' by Emily Perl Kingsley) It was not until Matthew was three weeks and Thomas was five weeks that they were well enough to come home. Those five weeks at National Women's were very hard with all the ordinary babies around and the mums thrilled with their wee bundles. I used to put on a brave face and carry on as if this was something that I was coping with. However underneath I was hurting like crazy and wishing my babies were like their room mates.

That hurt has continued and there have been days when I wished I did not have to get out of bed and by the end of the day I would often collapse into bed in tears, both emotionally and physically exhausted as I had difficulty coming to terms with the fact that the two children we had were not the two we were expecting. I even told the developmental paediatrician that I would be happier if they were both dead. As time

goes by I still have days when it suddenly hits me again and I feel low and wish I could turn back the clock. Although I love Thomas and Matthew for who they are I still feel sad for them and the rest of the family and what the future holds for us all. It still feels that we have been denied the chance at enjoying what is usually considered a normal life.

On top of the feelings of grief we have also had to contend with numerous appointments at Starship and Greenlane Hospitals together with the usual visits from a SLT, Developmental therapist and an early intervention teacher. With two children requiring appointments for hearing, vision and heart defects the visits to hospitals, doctors and specialists soon add up and often require some juggling of work commitments and other children adding to the feeling that it is all too hard.

However we continue on taking one day at a time and are truly grateful for the support of family and friends without which we may not have made it this far.

I have also found other families with children with Down syndrome to be very supportive and inspiring.

In writing this I have been as honest as I can about how I feel. I only want to tell my story so other people having a hard time know they are not alone. Please do not be judgmental but understand it is not always easy to accept something that is not what you assumed you were going to get.

*Alison Whittington
North Auckland*

**“ I have been as honest as I can about how I feel.
I want to tell my story so other people having a hard time know they are not alone.
Please do not be judgmental.”**

Initially the world crashed around our ears and we were devastated.

I kept questioning our Pediatrician for months afterwards as I was positive that he had made a mistake with the diagnosis somewhere along the way!!!!

I hid away for ages and believed that my wee girl would never see a Wiggles concert or go to a birthday party as I most certainly wasn't going to take her out in public.

Every time I did venture out (with my husband at my side and Anna well hidden behind a UV buggy cover) I returned feeling emotionally bashed and beaten as the pain was so intense.

My dreams were shattered, I cried for months and months, but outwardly pretended that everything was okay (for those who were brave enough to ask!!!).

Twelve months down the track and acceptance has come slowly, but surely.

Thankfully we both have incredible families and they have accepted Anna right from the start and continue to play a huge roll in her life.

Anna is the joy of our life and charms us constantly with her amazing perseverance and sense of humour. Her zest for living proves infectious to those around her and we feel so proud to be her parents.

*Rose Welland.
Nelson*