

## INTRODUCTION

Hi and welcome to the Cerebral Palsy Foundation's ParentWise Podcast series. I'm Robyn Cummins.

We've talked a lot about children with a disability in the ParentWise Podcasts, but what happens when you're the brother or sister of a child with a disability? Today, Mum and physiotherapist, Jaye Chadwick, shares her insights about what she, her husband and her family have experienced and learned about being a brother or sister to someone with a disability.

## HAVING A SIBLING WITH A DISABILITY

Hi. I'm Jaye Chadwick, Mum to four children including 10 year old Kate who has cerebral palsy. I also have three older children who don't have a disability.

Being a sibling of a person with a disability is often difficult and knowing how to manage those challenges is an important part of parenting children with and without disabilities.

When Kate was first diagnosed, my son James was seven years old, my oldest daughter Emma was six and Hannah was three.

My husband and I explained everything to them in terms they could understand. As they've grown older, we've continued to explain more as they've asked us various deeper questions. From the beginning, we explained it was no one's fault that Kate had her disability and that it could have been any one of us.

Kate was unlucky but lucky in other ways and any one of us could have been Kate. We asked the children lots of questions like how would they feel if they had a disability?

How would they like to be treated? How would they like to live life with a disability?

As my other children grew older they had to face the issue of always having to share me, their Mum, with their younger sister. This has meant not always having me around to watch them score goals at Saturday sport and realising that Kate's needs may have to come first, most of the time.

Having Kate in our family has also meant that her siblings can't always have relaxed and spontaneous holidays with her.

They've had to accept that holidays and family outings usually require a lot of planning and someone will always have to be around to help Kate.

My children also worried quite a bit about the reactions they would get when they introduced their peers to Kate.

While their school friends were always a bit cautious at first, they found interacting with Kate much easier once they got to know her better.

James, Emma and Hannah also wanted to know how to respond in a medical emergency so they all took it upon themselves to do their Senior First Aid and Surf Life Saving certificates.

As they've become older, my other children have taken on leadership roles at school and grown into mature, independent and resilient teenagers.

I believe that having a younger sister with a disability has contributed a lot to this.

## HOW IT WORKS FOR OUR FAMILY

Being the youngest in the family has meant that Kate has to fit in with what has already been set as our family norm.

Luckily, Kate also has an unusually brilliant, patient and super-caring close sibling who just loves spending time with her and involving her in things she does. She draws her friends to Kate and is very positive about her.

Now that Kate is getting older too she has her own set of friends at school, Saturday group, respite and Conductive Education. She also has three family friends with whom she has a close bond. They care for Kate for a day, an evening or a few days at home.

Like most children, Kate feels comfortable in various places and especially with other people she's happy to be with and who she knows will be able to care for her.

Kate's siblings are positive about her but there are some situations where they do become a little frustrated, especially if she interrupts their time with Mum or changes the ambience of a situation.

This is usually most obvious at mealtimes especially dinners in restaurants where Kate does need a lot of assistance.

Also, on evenings out with other families, the group usually split into parents talking and the children hanging out together. As teenagers, they want to do things without Kate - not all the time, just more of the time - so Kate sometimes stays with the adults.

In this situation, the others want time to have their own fun and not feel responsible. They sometimes find Kate an intrusion when they are trying to do homework and they wish Kate didn't take so much time to manage, but accept that her needs won't go away.

On the positive side, they feel Kate has made them a better person, but also wish for Kate's sake that she didn't have special needs.

They've also told me in the past that dealing with Kate's issues as a team has brought us together as a family.

## SOME STRATEGIES

You might be wondering what you as a parent can do to give your children without a disability the time and attention they deserve when you also have a child who needs special support.

One of the most effective things that we did was to implement 'parent time'. It used to be called 'Mum and Dad special time' where each of our children has one on one time with Mum or Dad.

This might involve driving to netball, going for a bike ride or run, or having favourite food or drink like a milkshake or sushi.

Touching base with each child by tucking them in, saying good night or asking, 'How is such and such going?' is also important.

'Let's talk about our day' is a dinner time ritual where we each take it in turns to talk about the best and worst thing that has happened that day.

It can be quite a funny and it also gives us a chance to find out what is happening for member of our family and what is important to them and what is not.

My husband and I are always praising the children for taking on extra responsibilities and for working so well in our team. We value their inputs and always tell them how important it is to us.

Also, if we have certain issues with Kate we will talk about them with the other children to find the best approach.

You'll be amazed at how many good ideas they come up with and they can also feel involved and part of the outcomes.

All the children are a big part of our approach to problem-solving but they also realize as parents we have the final say.

We also respect their need for time out from Kate.

Respite is a huge part of all our lives and enables the rest of the kids to have a bit of family time to go mountain biking, kayaking or trail running.

And finally, would I do anything different in hindsight?

Yes, I would have started in-home respite earlier if I could have found the funding for it.

As it turned out we couldn't get any respite funding until Kate was school aged. We asked family and friends to help, mostly after Kate went to bed, so that we could go out and have a break. I'll be speaking more about respite in another podcast, so stay tuned.

## CLOSE

Thanks for listening. We hope you've found these strategies and ideas useful.

You can download or listen to more episodes in the ParentWise Podcast series at the Cerebral Palsy Foundation's website - [www.cpfoundation.com.au](http://www.cpfoundation.com.au)