



Cerebral Palsy
ALLIANCE



Follow Your Instincts

Parent insights on having a child with a disability

Contents

ACKNOWLEDGEMENTS

Our thanks to the families who kindly shared their experiences so that others may benefit.

CEREBRAL PALSY ALLIANCE (CPA)

CPA is a leading provider of early childhood intervention services, family-centred therapies, equipment, technology, life skills and other support for children and adults with a disability and their families.

Your child has a bright future and we are here to help make that happen.

CPA is a not-for-profit organisation and a registered provider under the National Disability Insurance Scheme (NDIS).

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Note: the children featured in photographs in this book are not those of parents interviewed for the project.

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Introduction

Parents of a child with a disability often say that talking to other parents and sharing experiences, information and practical ideas gives them the encouragement and strength to pursue what is needed for their child’s wellbeing and future opportunities.

This book is a collection of reflections from parents about their birth experience, how they managed growing concerns, and how they shared their child’s diagnosis with others. Also included are observations and tips about finding and working with different professionals and services, as well as managing the impact that disability has on parents individually, on their relationship, on their child, and on the rest of the family.

Many of the children whose parents were interviewed have cerebral palsy, but these experiences and observations are often common to parents of any children with a disability. Parents were asked to reflect on the first six years of their child’s life. Insights were gathered from parents in rural and metropolitan areas, and from different backgrounds and beliefs.

For some parents, memories of the supports they received from medical and community service groups were positive. For others, the memories were more painful. While each person’s experience was unique, one of the strongest messages given by the participating parents to other parents was to have confidence in your instincts about what is right for your child and don’t be afraid to seek the information and support that you need from family, friends, healthcare professionals and disability support services.

Our thanks to all those who participated in this project – for your time, patience and compassion.

Have confidence in your instincts about what is right for your child and don’t be afraid to seek the information and support that you need from family, friends, healthcare professionals and disability support services.

PART 1

Early Days



“My head was full of questions. ‘How could it be?’ I wondered how I would deal with it if she were severely disabled... [and] the impact that it would have on the family and on my husband.”

Birth experience

PARENTS SAY...
Birth experiences vary widely

Parents of children with a disability have a wide range of birth experiences.

For parents of babies born prematurely, the days afterwards can be a blur of medical crises and neonatal intensive care.

Some parents may face complications in the days after their child is born, while other parents may experience a trouble-free birth.

Whatever the experience, the memory of their child's birth and the succeeding weeks is deeply etched in the minds of most parents.

SEEMINGLY TROUBLE-FREE BIRTHS

My son was born a healthy baby at full term. He wasn't diagnosed until nine months later.

There was no real incident around her birth... a quick birth. The doctor didn't pick up on any issues. Everything about her was normal, except her head circumference was a little less than it should have been. Everyone documented this but no one commented. Leaving the hospital... she was eating and drinking well. I was breastfeeding her, so no issues there.

PREMATURE BABIES

She was premature. I'd had two great pregnancies before. They tried to stop the labour. They said that if I could get to 30 weeks then it would probably be okay. Nobody said anything about the problems with premature babies.

He was born at 25 weeks, very premature and about 800 grams. I had been bleeding for a couple of weeks, just small amounts. I went into hospital with small contractions a couple of days before he was born. He was a normal delivery and was put straight into a humidicrib. When he was a week old, he had a scan and the doctors found a brain stem haemorrhage.

Why he came early? What is the cause? No one knows why. The doctor's fault or my fault? I think it's both. My cousins, who are doctors said, 'Why did they wait four days to have him? They should have induced you and made you have him straight away'. 'No' I said, 'They wanted to protect the lungs. They told us they wanted to make the lungs more mature'.

DRAMATIC ENTRANCES TO THE WORLD

It was a perfect pregnancy. Towards the end I started feeling a lot less movement... She was born with no heartbeat, with no colour. She was white. No blood left in her. She had haemorrhaged into me in the womb.

We decided on a caesarean. I hadn't had a caesarean before. I said OK, we would do it the easy way for her. So I opted for that, which nearly killed me because I lost 2 litres of blood. Anyway I got out of it all right and my daughter went into intensive care. They said she was fine.

It was a normal sort of pregnancy. About seven hours after the birth, he had a medical crisis and was taken to the children's hospital.



BIRTH EXPERIENCES: KEY POINTS

- For parents with a child who has a disability, birth experiences can vary greatly – from a blur of medical crises to having no awareness of the disability
- Disability may not be apparent for some time following the birth.



Growing concerns

In the early days, some parents saw no indication that their child had a disability. However, in the following months they slowly felt an inkling of concern.

Some health professionals avoided definitive answers when asked for help. Many of the parents experienced a sense of feeling stuck, wavering between wanting to know and being afraid to know.

Some blocked the growing concerns, thinking that surely everything would be okay in the end. Others experienced frustration and anger at not being able to gain confirmation.

For some, there was a sense of disbelief... This couldn't possibly be happening to them.

Many parents found that the expectation that the new baby would be enjoyed and fussed over by family and friends ended in disappointment as the growing, and seemingly endless, hospital visits and other medical tests and interventions took precedence.

It was often an exhausting and uncertain time, where their little baby was handled and examined by countless strangers within the medical field. Some babies also had a range of other problems, such as difficulties in feeding and sleeping.

PARENTS SAY...
The early days can be difficult and uncertain

DIFFICULTIES IN HEALTHCARE SETTINGS

When he was two weeks old, I noticed something wrong. He would not stop crying and wouldn't eat. He was sleeping no more than eight hours a day in small blocks. I went to a sleep clinic to try and find out what was wrong, but nothing helped.

Mainstream services that are approached for support may be at a loss to assist. It is easy in these circumstances to feel lost and alone as a parent. If it is your first child, it may be easy to blame yourself, believing that there might be something wrong with your parenting skills.

When I took him to the baby clinic for his four-month check-up, the nurses noticed that he might have cerebral palsy. Afterwards they said it wasn't their business to tell me, 'It was the doctors' responsibility'. When I asked the neonatologist or paediatrician whether he had cerebral palsy, they said it was too early to tell.

There were lots of complications when he was born... they didn't tell me anything. I didn't know until he was about nine months old. He didn't sleep so I phoned the doctor for an appointment. I said, 'What's wrong?' She said the specialist would tell me. I waited another two months to see the specialist and he told me what happened with him.

It was quite a fight to get somebody to take it seriously. It took a private paediatrician... We're very grateful to him because he said, 'Yes, I can see what you're saying'. Everyone else seemed to think, 'First time mother, she's over-reacting'.

It was very disappointing not being heard by these doctors. Especially his epilepsy being undiagnosed. What damage has that done to his brain? I'd say, 'He's staring into space', and they just go, 'It's a mum over-reacting' or, 'It's just reflux'.



WHEN THINGS ARE NOT QUITE RIGHT

At four to five months I saw that he wasn't using both hands together. That was the first sign. We spoke to our GP about it and she said, 'Oh that's quite normal, he's clearly going to be right-handed', which in hindsight is a ridiculous thing to say. At six months I brought it up again and said, 'I really think we need to talk to a specialist, get a referral to a paediatrician'.

I went to the clinic, and they noticed that her head circumference was about 2½ cm less than it should have been. The GP said 'Don't worry, some kids just have smaller heads, everything is fine'. She actually looked OK. All the milestones were fine. I am a health professional and I didn't pick up anything. I guess when they get a little bit older and start using their limbs in a more meaningful way, that's when it became noticeable.

I became concerned when he was about 19 months old. I did not want to tell anyone that my son had a disability at this point.

It was hard because I had two nephews that were around the same age. I'd see them reach their milestones and think, 'That's where he should be. That's what he should be doing'. Even though you try not to compare.

THE UNCERTAINTY OF THE FUTURE

After his birth we were told that there was definite brain damage but we didn't know how it would progress over the months. We were aware that there was something wrong, but we had no idea it was cerebral palsy. At the time we didn't know what it meant.

Before we left the hospital, some ultrasounds showed that there was damage in the muscle control area of his brain. They didn't say cerebral palsy. We didn't know whether he would be OK. It was just a waiting game, but they still never said cerebral palsy. So you just imagine some little thing.

They said he had a 50% chance of living at that stage and had a great risk of being deaf, having cerebral palsy and eyesight problems. After he had the bleed we knew the chances he would have cerebral palsy were much greater.

Our paediatrician rang us and said, 'It's not what I expected'. She scared the hell out of us. She said, 'You need to come in and we can go through it. I don't want to tell you over the phone'. Then we had to wait – I don't know how many days. You're just racking your brain. We spoke to her again and said, 'You really need to see us so we don't go crazy in the meantime'.

"We were aware that there was something wrong, but we had no idea it was cerebral palsy."

Early Childhood Early Intervention (ECEI)

The ECEI approach has been designed to support children aged 0–6 years who have a developmental delay or disability and their families and/or carers. The National Disability Insurance Agency (NDIA) have appointed ECEI partners around Australia to help guide families and carers to the most appropriate supports available for their child when concerns have been identified.

To find your local ECEI Partner, visit www.ndis.gov.au/contact/locations



GROWING CONCERNS: KEY POINTS

- You know your child, and it is okay to seek help if you have concerns
- If you find that you are not getting the support you need from your healthcare team, it is okay to get a second opinion or try other support services.

Diagnosis and adjustment

Finally, a doctor confirms the words that parents may have been dreading: 'Your child has a disability' or, 'Your child has cerebral palsy'.

Many of the parents we spoke to had never heard of the condition being diagnosed, be that cerebral palsy or another disability. Following the diagnosis, many doctors provided too much technical information, and others not enough.

For some parents, diagnosis was a relief. At last they knew and could seek out support from disability services. Still other parents experienced disbelief, shock and guilt: 'Why has this happened to me? Did I do something wrong during the pregnancy? Are the doctors at fault?'

Some doctors were very casual in their delivery of the diagnosis. Many parents were not offered counselling support to help cope and process the news, and it was often a devastating experience when they were left alone with their thoughts and their emotions. Many parents went straight onto the internet, where the nature and volume of information was confronting and overwhelming.

Some parents felt a betrayal of trust when they realised that the health professionals suspected their child had a disability, but did not say anything.

Questions about the future were in the minds of many parents. Will my baby walk and talk? How dependent on me will they be? What quality of life will they have? Grappling with medical terminology was often another battle – spasticity, dystonia, hemiplegia, microcephaly, and other jargon. There seemed so much to understand with not nearly enough explanation.

Until recently, cerebral palsy was often not diagnosed until a child was 12 to 18 months of age. Advances in diagnostic methods mean that babies can now be diagnosed with cerebral palsy or 'high risk of cerebral palsy' (where cerebral palsy is suspected but the diagnosis is not yet certain) as early as three months of age.

PARENTS SAY...
Diagnosis can be met with a range of emotions

WHEN DIAGNOSIS IS A RELIEF

They were reluctant to diagnose. Subsequently the GP made the neonatal guy tell me that he had cerebral palsy. Before he was diagnosed, I felt awful because I found it really hard to do things like bathe him. I thought it was me being inadequate. After the diagnosis it was easier, because it was acknowledged.



*“You sort of hear about it but it’s the
‘It could not happen to me factor’.”*

WHEN DIAGNOSIS IS A SHOCK

We were referred to a paediatrician. Two days later he looked across the table and said she had microcephaly and cerebral palsy. It was like hitting a brick wall at a 100 km an hour. It’s like what people say when you’re in shock: you feel like you’re in a movie and you are on the outside looking in. I was having this experience, was watching these people, but the main character was me.

You hope that everything will be okay. I was actually keeping in touch with another couple from the hospital who had twins. My son was achieving the same milestones as one of their children. But when we went back for our one-year-corrected check at the hospital, they said he had cerebral palsy.

They told me to go to a physiotherapist because he was 2½ weeks premature. At the end of a physiotherapy session, just before he was a year old, the physio said that he would probably never be able to play soccer with his dad. I said, ‘What?’ and she said, ‘That’s what it’s like with cerebral palsy’. I had no idea that he had cerebral palsy. I got in the car and drove with tears running down my face. I cried all the way home.

I took him to a centre for predominantly kids with an intellectual impairment. The physios knew the problem as soon as they touched him, but because they are not doctors they are not allowed to diagnose. Because they couldn’t tell me, they said to me, ‘I don’t think this is the place for him. I think he would be better managed at a physical disability service’. I didn’t twig that it was cerebral palsy. It wasn’t until my son was seven months old that the doctor said he definitely had cerebral palsy. So that was a bit of a shock.

We were told his diagnosis, and a very short prognosis that he was going to be severely affected – brain damaged and physically disabled – pretty much in just a ward-style visit. So it was dropped on us.

The doctor gave us that information and then continued on with his rounds.

She was diagnosed at about nine months, including three months prem. The doctors, the paediatrician, had never said anything. Then I went to the women’s hospital for a check-up for premature babies. The doctor went, ‘Oh, your baby is floppy and she may never walk’. It shocked the daylights out of me because there was no softness about it. The doctor was surprised that the paediatrician hadn’t told me, but apparently that is quite common. I knew there were things wrong, but when it’s your own baby you don’t admit it. I just thought she was preemie and she would get better as she grows.

You don’t want to go scaring people, but there is never any second scenario painted at the prenatal classes. ‘Everything is fine. You’ll have beautiful babies’. There is never anything mentioned about the possibility. After it was over we sat back and thought, ‘Nobody ever mentioned that anything could ever go wrong’.

When my first child was diagnosed, I was just dumped out, shocked. I didn’t know anything about disabilities. I thought they could have surgery and fix it. We were naïve at that stage and just trying to cope with the intensive care. Over the next three days we didn’t eat, we didn’t sleep. My husband just went and researched everything on cerebral palsy. They said they didn’t know the severity of PVL [Periventricular Leukomalacia]. It could be just seizures; it could be intellectual; it could be physical. It varies in each child.

PROCESSING THE NEWS

He was diagnosed at the hospital where I gave birth. They have a follow-up program when they are one year corrected. The assessment went for about 2½ hours. They look at what he’s doing and what he should be doing for someone his age.

After that assessment I walked out thinking, ‘What the hell is cerebral palsy?’ I was very naïve and ignorant. I had no idea that cerebral palsy can be someone who cannot catch a ball or it can be someone who cannot do a single thing for themselves.

At the first mention from the medical professionals about mild intellectual disability, I think I retreated right back to the cave. Sort of like blocking your ears and humming. It was too awful to contemplate. I thought, ‘God, I can handle the physical stuff, but not the intellectual stuff’.

At birth when the doctor tells you that your son has brain damage you think it’s not happening to you. Then I took him home thinking, ‘Well okay. We’ll do the best that we can and just see what happens over the months’. I just wanted to talk to people, find out as much as I could about cerebral palsy.

We went to the health centre and a movement specialist referred us to a paediatrician. My husband came as well, which was really good. The paediatrician was excellent. After he told us, he left the room for ten minutes so that we could talk together and cry. Then he came back with coffee for us, and talked some more. We saw him on a Tuesday and he told us to think about what he had said and to come back two days later on the Thursday with all the questions. That was so good. He was also very positive about the things that were good, very enthusiastic about the things that he thought she would be able to do.

So you get over having a preemie and going through all that and then you have to go through it all again. It took a long, long time to come to terms with it. There was no reason why I had him preemie, but I think there was a lot of guilt for me. Maybe I did this; maybe I did that.

WORRYING ABOUT WHAT'S TO COME

The neurologist said it was global damage, brain damage. He said in the event that she was to survive she'd have very little quality of life. It was a very bleak, bleak picture. Then he kept flip-flopping and saying, 'But I have seen families where it's been amazing'.

My head was full of questions, 'How could it be?' and, 'How can she have that if she has been so well all along?' We found out later that I had a flu virus at 15 weeks that crossed over and gave her the brain injury. I wondered how I would deal with it if she were severely disabled. She is the fourth child in the family. All the other kids – how would they relate to her? The impact that it would have on the family and on my husband.

I didn't know what to expect. They couldn't tell me if she would walk. They couldn't tell me if she would talk. You don't know if they are intellectually disabled as well. The biggest thing to me was, 'Will she ever understand that I love her?' You don't know what the future holds.

COPING IN DIFFERENT WAYS

I was doing all of the thinking stuff, my husband was doing all of the feeling stuff. He never left her. I would leave sometimes because I was so drained and still on all the drugs that they gave me for the pain. Through the night, he'd be reading to her, singing her songs, cuddling, kissing her. He would sit and tell her stories – just talk to her for hours.

It became clearer as he was getting older there was something wrong. Denial got me through the first year.

We were in NICU... She hooked her hand around my husband's finger. It looked to me like she was saying, 'I'm going to hang on Daddy, don't worry'.

There is an extra stress in your life. You can't have the family you wanted or do the things you wanted. You don't do things that other people do or things you thought you would have done. There is a lot of financial strain. No one has a charmed life and who knows what other stresses would have happened? You deal with your life as best you can.

It's interesting, because when the paediatrician told us the situation with our son the day after I gave birth, my husband collapsed in a heap. I had never seen him that way before. He was quite upset. Understandably so, but for some reason I held it together. I thought I've got to do this for our son. I suppose that's why I suddenly fell ill soon after.



TIPS FROM OTHER PARENTS

Tips from other parents who have navigated similar situations are included throughout this booklet.



See Part 3 (Information and Services) for tips on finding information and working with your healthcare team from diagnosis onwards.



Some parents benefit from counselling and being able to talk through their experiences. Speak with your healthcare team or your local GP about options in your area. Carers NSW also offer several support options at www.carersnsw.org.au/advice/talk-things-over.



DIAGNOSIS AND ADJUSTMENT: KEY POINTS

- Diagnosis can be met with a range of reactions and emotions
- People may cope with the news in many different ways
- It is common to have concerns about what the diagnosis means and what the future will hold.

Others' reactions and support

Parents told us that another challenge arose when telling their extended family, friends and work colleagues about the diagnosis.

Some people were uncomfortable at the news; some avoided the parent, as they did not know how to react or what to say. Others brushed it aside with comments that everything will be all right in the future, or other inappropriate suggestions or comments.

Within some family networks there was a spoken or unspoken insinuation: 'This has never happened on our side of the family'.

In some cultures it may be shameful to have a child with a disability, and this may discourage parents from seeking support from services. Some parents felt that blame was apportioned by their communities due to a belief that the parents, by having a child with a disability, may have been being punished for some transgression.

On the other hand some parents received wonderful practical and emotional support from family and friends, which helped ease the stress of coping with others' negative emotions.

PARENTS SAY...
There's no 'right' way to share the diagnosis

BEING OPEN ABOUT DIAGNOSIS

I just came straight out and told our family and friends. Anyone who has had a child would have twigged that something wasn't quite right. My friends and family handled it better than my husband's family who said, 'What's that?' I still have to explain to the mother-in-law. I think my family and friends have been a lot more aware. Aware of the person, rather than the disability.

I just told them and cried a lot. I didn't know what to expect.

It was a birth diagnosis, so we had lots of family and those networks you have when you are pregnant. So it was never a conscious thing for us to have to tell anybody. It was all pretty known. You find out who your friends really are. There are a lot of well-wishers but, as time passes, they drift away. We've never really had a problem with confronting people about it. Always been really honest and upfront about it.

I found it less difficult to tell people about my child's needs once I had begun to accept it myself. I hid behind her prematurity for a long time. Now I use her to raise awareness of cerebral palsy and adapt my explanations to the audience.



“My close friends were very positive about all the things my daughter could do and how to deal with the issues. Our family tried really hard to be supportive but they had to deal with it too.”

CHOOSING TO NOT SHARE THE NEWS

I didn't say anything to anyone. Over time our older daughters worked it out.

I couldn't tell people... not for a while. To say 'cerebral palsy' was a hard thing. A lot of older people, especially in the Italian community, just aren't aware. We used to see them and it was like, 'Oh, he's not walking yet', and we just used to say, 'Oh, that's because he was premmie'.

We didn't tell our family back home (overseas) for a while. We thought maybe we didn't have to tell them. Our son may be walking and we would tell them later. I had to tell my mum when he wasn't walking by the age of four. She didn't care, as long as he was alive and he was speaking to her on the phone. He could tell her what she wanted to hear... she couldn't see his disability.

We didn't say, 'He's got cerebral palsy', because nobody knew what that was. You blame yourself at first. I'm past that. Over. History. I've moved on. I don't blame myself. Wouldn't have it any other way now. I got quite sick. That was my immune system just breaking down. I was so strong on the outside and I just kept on going. I suppose my body just gave in. Now I just take it day by day. I am his strength.

EXPERIENCING VARIED REACTIONS

My parents were not helpful. They were in denial, especially my mother. She believed that there were simple explanations. If I overcame these, there would not be a disability. I've learnt not to take this to heart now. I've accepted it and moved on.

My brothers and sisters were much more help. They did not know anything was wrong but they listened and tried to be supportive. My friends were very good. Some would listen to my stories and others would offer help, such as babysitting.

My close friends were very positive about all the things my daughter could do and how to deal with the issues. Our family tried really hard to be supportive but they had to deal with it too. My parents are in England. I had in-laws, but they were really struggling to get their heads around it. They kept my daughter at arm's length, which I really didn't like.

It was a shock when I told my family. There was just question after question. We didn't know the answers ourselves.

I really had no idea what it meant. I thought it was something that was going to go away. I told people, 'They think he's got cerebral palsy'. Friends would say, 'He looks fine'.

All the family are very loving towards my son, but with grandparents... The relationship is there, the love is there, but there is a lot of misunderstanding of how difficult 24-hour supervision is. They are just unaware of the responsibility and not normally prepared to take it.

My husband's parents, they always say he looks fine, 'He's just a bit slow'. They think that will make me feel better. Do you think if that was really the case I would be spending half my life at the disability service? Especially now that he can walk, they think there's nothing wrong with him. But I guess maybe as he gets older... We're at that age now where a lot of kids start talking. This is the stage where people start to say, 'Yeah, there's something a bit different about him'. He's not talking and my two-year-old talks. I suppose until now he was a little baby and little babies don't really do anything.

There were more than enough people who wanted to talk about it. Sometimes you did not want to talk about it!

We're not too hard on people, but 90% of the people out there have never come in contact with someone with a disability. That was tough for me at work and still is. I have this life at home where everything is disability, that's just normal life for us. I just don't even mention it. It's too much work.

MEETING OTHER PARENTS

At first I didn't want to meet any other parents. I didn't want to cloud the tiny bit of optimism that I had by seeing any other child with a disability.

Meet or connect with other parents for your own sanity. I get a lot from talking to the mums. You find that you can ask other parents anything and they're all willing to share. It's hard work. That's reality. You can be terribly honest and you can say it's too hard.

We joined a parent group at Cerebral Palsy Alliance. The mums – sometimes dads – would be in one room having a cup of tea, and the children would be in another room. It was such a relief to sit down for an hour or two and have the children looked after. Sometimes they would have a topic for us to discuss, but at the beginning it was just come in and get together. Our children were all similar ages.

I met parents through a support group and we stayed in contact. You meet people in waiting rooms. We did a workshop and I met some girls there that I have kept in touch with. I go to two playgroups. We SMS and connect on Facebook all the time. We tell each other what works and what doesn't. One of the girls gets her services at other places. It's good to see the differences.



OTHERS' REACTIONS AND SUPPORT: KEY POINTS

- Who you choose to discuss your child's diagnosis with is your own choice
- You may receive mixed reactions from people. Help them understand what you need and how they can help
- Meeting others who understand disability or are sharing similar experiences can be helpful
- It can be extremely helpful to find positive mentors – parents and professionals who can share with you their experiences, advice and support.

PART 2

The Family



“With a normal kid, you always have the main issues around how you discipline your child. With our daughter, there are completely different issues. You and your partner will have very different ideas, so you're always dealing with that.”

You and your partner: parent relationships

All normal relationships experience a range of demands and stresses. The parents we spoke to found that having a child with a disability brought additional emotional and physical demands.

Some couples who had been planning their family for some time felt that their dreams had been shattered. This was not the baby experience they were expecting. The grief around the loss of this 'family dream' was painful.

Some found that their partner withdrew emotionally and was less available to them as they struggled with their grief. For many, these losses were compounded by the loss of social opportunities, friends, careers and jobs in order to provide the necessary support for their child. Financial demands increased to cover costs of medical intervention, therapy and equipment.

For some couples, the ultimate outcome was an end to their relationship as they struggled to deal with their own emotions and to provide their child with the needed services and supports.

For other couples, the emotional and practical challenges brought them closer together and strengthened their relationship. They embarked on the difficult journey together. These couples expressed the importance of close communication and time out, both as a couple and individually.

PARENTS SAY...
Having a child with special needs affects other relationships, too

RELATIONSHIPS SOMETIMES GET STRONGER

We were married very young and our son was born when I was 22. My husband has always backed any decision I have made about our son. If anything, it has made us stronger. We both need each other's support. We have nearly lost our son twice, so we greatly appreciate the good times. We understand that we both feel overwhelmed, devastated and grieve for what could have been.

I think it made us stronger. We wanted to do things together. My husband never told me, 'It's your fault'. He's different to me. He doesn't say much but he will go along with what I want to do.

There was sort of a bit of frustration in the beginning because we both didn't know what to do and how to go about it. But I think communication is so important. Once you talk it through and compromise... It's up to the stage where it is just great. We work as a team and that is how it should be. But also the fact that we were never in denial from the beginning. That's also very important. It took a while for my husband to accept it. But not long. After that it was fine.

It was like we were punished, but it didn't happen to me. It happened to all of us – the family. At first my husband and I didn't deal with it together. We had our own ways of dealing with it. Then it probably brought us closer.

My husband makes sure I have time out and I make sure he has it, too. I would have been working if I did not have a son with cerebral palsy. I would like to work a bit. I never wanted to work full time as a mother, but I would have worked.

With my husband, it has both strengthened the relationship as well as weakened it. Strengthened only because you have to. Weakened because all conversations are around our son, or interrupted by him. Most fights are over him, and most of the spare time is spent with him. It always comes back to him. It's hard, because when you do have time together you are so tired and in a zombie-like mode. We argue like most normal couples, but over different things.



RELATIONSHIPS ARE SOMETIMES STRAINED

My husband takes the back-burner a bit. Sometimes he says, 'What about me?' He tried to be stronger than me. But I know deep down... it's a hard thing. Very hard.

I was working at the time, but I found it was too much for my partner to bear on her own. So I made the decision that we spent the preschool years with him every day, doing what we needed to do. That was our decision, but it did take its toll on our relationship because we're not together now. We are still very close. It's the same priorities, but we are not together as a couple.

There was a lack of understanding and sympathy from my child's father. We are now separated.

FINDING TIME FOR EACH OTHER CAN BE DIFFICULT

It takes time away from your partner. With a normal kid you always have the main issues around how you discipline your child. With our daughter there are completely different issues. You and your partner will have very different ideas, so you're always dealing with that.

Our daughter is a great kid but she is very time-consuming. Other kids her age will dress themselves or brush their teeth but we are doing all those things for her. She is a very messy eater but very determined to do it herself. Taking her out for dinner, she can become very loud at a restaurant or anywhere really. Then you start dealing with other people's reactions to her.



What parents recommend based on their experiences...

- Take one day at a time and take that day positively. You don't have control over the future, but you do have control over today
- Know that it's a learning experience that never stops
- Be kind to yourself. Don't continually focus on what needs to be done. Remember to look at what you've accomplished
- It's important to have time out – make sure that you each have time to relax and breathe
- Start the day with a bit of time for yourself. I get up at 5.30am four mornings a week, meet a friend down the road and walk for an hour. I make sure that I have time at the beginning of each day because I know I won't have it at the end
- Don't underestimate the value of counselling or seeking professional mental health services, if needed
- Keep in mind the feelings and needs of your partner and other children. Remind them that your child doesn't get more of your love, just because they get more of your time
- Try not to get stuck, crying, 'What happened to us?'. Do something about it
- Find a really good babysitter who is comfortable looking after a child with a disability and make time to go out together
- Stop and smell the roses. Take advantage of the fact you've gained a special appreciation for the little miracles in life that others take for granted
- Be honest with your feelings. You can't be a super-parent 24 hours a day. Allow yourself jealousy, anger, pity, frustration and depression in small amounts whenever necessary
- I go to work three days a week because that's a chance for me to get away from it. When I go to work I don't have to think about it. I don't have to be at the services, I don't have to be at playgroup. My mum and dad babysit while I'm at work. Family is important. You know they have his best interests at heart
- Keep and use a sense of humour. Cracking up with laughter can help you from cracking up from stress
- Keep things in perspective – life moves on, things do get better and different.



YOU AND YOUR PARTNER: KEY POINTS

- Set aside some time to be together as a couple and also time to pursue your individual interests
- Accept that you will have differing viewpoints and different ways of handling situations at times
- Recognise and acknowledge each other's contributions to the family
- Listen to one another – whether the communication is spoken or unspoken
- Consider seeking professional help for your relationship, as well as your child, if needed.



Brothers and sisters

PARENTS SAY...
Sibling reactions are mixed

Children at certain ages may exhibit attention-seeking behaviour as they notice their brother or sister with a disability seems to get all the attention.

Others may feel the burden of expectation, real or imagined, that they need to look after their brother or sister at the expense of meeting their own needs. This can trigger a feeling of further loss for them. Some children just accept the situation and are upset when others don't treat their brother or sister as they do.

The response of your other children will vary according to their age and personality. The parents we spoke with recalled a wide range of feelings and behaviours, such as:

- Embarrassment
- Protectiveness and nurturing
- Jealousy
- Anger at their parents or sibling
- Withdrawal from family life
- Treating their sibling as any other.

SIBLINGS MAY EMBRACE THEIR FAMILY MEMBER WITH DISABILITY

She is queen bee. She rules the roost... a lovely little girl with a lovely personality. She is very social, has a moderate physical and intellectual disability, but she steals the show and steals people's hearts. She is a great trier and tries to keep up with the pack. [Her siblings] really dote on her and fight to be with her. As they get older it may change a little bit.

Our younger son is our blessing. If he didn't turn up when he did, we wouldn't have had a second. He dotes on his brother. He's his guardian.

He's good with the other children. Intellectually he is OK, which is a big bonus. He can communicate, which is unreal. His younger brother is really rough with him, but he loves it and it has gotten him going a bit more.

SIBLINGS MAY EXPERIENCE STRONG EMOTIONS

I think my second daughter was angry at one stage. Why did I have her after ten years? That was one thing I couldn't explain to them. But I think now she has her own personality, and she has her own place, and I cannot do without her and I think they think the same. They're trying to help.

We have chores in the house. Sometimes it's, 'Who is going to help her get dressed?' 'It becomes, 'Oh, I did it last time!' So it's not all sort of rosy, but they are accepting of where she is at.

For his older brother, it was very hard... He changed a lot... He became really quiet and withdrawn. Having another younger brother has helped him heal as well I think.

The only negativity is when other people don't accept her as they do. They get upset. A girl made a comment once, 'What's up with her? Why is she like that?' They turned around and said, 'She's fine. What's wrong with you?'

SIBLINGS MAY NOT SEE DISABILITY AS DIFFERENCE

I haven't really had to really explain the disability to my other children. They just accept their little sister. They laugh at her when she does funny things. She is not naughty, but cheeky. They help with her daily routine. They realise that she is disabled physically, but that doesn't stop them playing with her... and making her part of the big family.

They act like normal brothers and sisters. There was a stage in development where he and the other children were on the same mental level and became closer. I call this stage 'twins' because they interacted really well. It is a trying time though, because the sibling eventually grows out of this stage and moves on without them.

Our other children came later and have grown up with him. They are basically beyond any disabilities. One questioned it about a year ago. 'Why does he walk like this?' He would try to mimic him, but they just play like any brothers. They know the terms, like brace and cerebral palsy. They hear that all the time, it's just a normal thing for them really.

"I haven't really had to really explain the disability to my other children. They just accept their little sister... They realise that she is disabled physically, but that doesn't stop them playing with her."

And the siblings say...

"I have a bond with my sister, like a friend."

"I like listening to my brother's funny laugh."

"My sister makes me cards, which are hard to read but meant well."

"I don't like it when my brother gets his way because he's crying."

"It's good because we can jump the queue at theme parks."

"There's less attention for me because my brother needs more time from my parents."

"I am inspired by my sister."

"He has a go at everything but sometimes gets frustrated."

"I try to calm down, take three deep breaths and remind myself it is not her fault."

"I enjoy playing games with my brother and watching YouTube."

"When my brother is in pain he gets aggravated."

"We have been through more stuff than other people, like going to the hospital."

"Having a sibling with a disability brings our family closer."



TIPS FROM SIBLINGS AUSTRALIA

Provide siblings with information about the disability.

Include them in family discussions.

Give them opportunities to express their feelings.

Provide them with skills to deal with difficult situations.

Spend one-to-one time with them

Acknowledge their contributions: help them to feel competent, but avoid too much responsibility.

Encourage their independence and a wide social network.

Celebrate their achievements.

Encourage 'normal' play between siblings.

Watch for behaviour that might indicate stress.

Arrange contact with other siblings of a child with a disability.

More tips and useful information can be found at the Siblings Australia website: www.siblingsaustralia.org.au.

PART 3

Information and Services



"I find that once you access one service, it opens the door to many others. It's really important to ask a lot of questions and find out as much as you can about what's available."



BROTHERS AND SISTERS: KEY POINTS

- Like their parents, siblings of a child with disability can have a range of reactions and emotions. They may need additional support, or they may not be aware of any difference.

Finding information and services

For many parents, identifying and accessing the services their child needed was a hit-and-miss affair. Searching for appropriate services was often challenging, as they may have felt ‘in a daze’, struggling emotionally with the recent confirmation of their child’s disability.

Some medical services did not offer appropriate referrals or information about support services. Mainstream support services that did not have specialist knowledge of disability were often less helpful than specialist support services. Many found this a frustrating, time-consuming and exhausting experience.

Multilingual written information was rare, which added to the void when parents were not fluent in English.

Some services required waiting times and other services, such as respite, were sometimes difficult to access at a level that was of practical help.

PARENTS SAY...
Seeking the right information and services is important

WANTING TO KNOW MORE IS COMMON

Every day, someone is in despair in a NICU room, trying to make sense of what’s happened and trying to become an expert in a very short space of time.

I wished to know the cause of my child’s condition. How to access the appropriate services so I fully understand the illness correctly – not so much blaming, feeling guilty.

I read up on it when he was first diagnosed. A lot of it is just experience. If he goes onto medication, I check it out. You have to be like that. Get off your butt and do a bit a reading. If you disagree with something, don’t go with it.

SOMETIMES, THERE IS TOO MUCH INFORMATION

Basically, it was a process of elimination. It was quite confronting when we got a lot of information on his diagnosis. You are looking at stereotypical cases and the outcome for stereotypical cases for this condition are really very grim. We found it was very upsetting and very frightening to actually get the right information. Luckily for us, our son is very un-stereotypical so we are very blessed in that respect.



“I read up on it when he was first diagnosed. A lot of it is just experience... Do a bit a reading. If you disagree with something, don’t go with it.”

MANY START ONLINE

I started Googling very early ... The very last meeting at the hospital was the first time cerebral palsy was ever mentioned. I said, 'I've heard about this group Cerebral Palsy Alliance. Should I get in touch?' The specialist goes, 'Yes'.

I jumped on the local mum's Facebook page and asked, 'Has anyone got a good special needs paediatrician?' I got a few recommendations. I just rang up and booked an appointment and then went back to my GP and said, 'OK you need to give me a referral for this person'.

I just Googled: 'child having difficulty with x'.

I'm on every CP Facebook group, Mum's Facebook Groups, NDIS groups. People ask questions, you pick up information.

I joined a couple of groups on Facebook. They act as almost an advocate. They would say, 'Ask this question next time you see your doctor'. I post questions, concerns, ask for information. I always get a lot of responses. Sometimes too many!

SOME HEALTHCARE PROFESSIONALS CAN BE UNHELPFUL

I thought once we got a diagnosis from the paediatrician, he would say, 'You need OT, etc', but he didn't really offer any information, no emotional or any other sort of support.

FORTUNATELY, MANY SERVICES ARE MUCH MORE SUPPORTIVE

I actually emailed Cerebral Palsy Alliance because I thought if I rang, I would burst into tears. They came out to the house soon after and got the ball rolling.

The paediatrician said, 'These are all the referrals, these are all the people we need to get you in front of, for everything'.

I find that once you access one service, it opens the door to many others. It's really important to ask a lot of questions and find out as much as you can about what's available.

The baby health clinic was supportive and helped us access services. The community nurse was also very helpful. I've tried private organisations, but I've found that they generally don't have the experience with cerebral palsy.

The therapist at the hospital referred me to other services. Meeting with other parents is important. You learn more from them.

I got the services for my child through TAFE's childcare services. They recognised my child's condition and referred him to a disability service.

I did not receive any written information in Vietnamese but I have seen professionals that helped me to understand my child's condition. I also shared my concerns and worries about my child's condition with other parents. I think I was lucky to get into the right services initially.

We've embraced early intervention. We've taken it by the horns and thrown everything at it. This year is going to be a big year for us because we really need to do as much as we can before school. You want him to feel like a normal kid and do what normal kids are doing, and that's not necessarily having a therapist come to your school or pull you out of classes.

Hunt around until you find the people who will be your advocate, who will go in to bat for your child.

"Hunt around until you find the people who will be your advocate, who will go in to bat for your child."



FRIENDS CAN BE AN IMPORTANT SOURCE OF INFORMATION AND SUPPORT

A friend referred me to early intervention. That was a really difficult stage. We were trying to cope with the diagnosis but not knowing what to do. I knew there would be a wealth of information but I didn't know how to access it. I made lots of phone calls. It was a case of ringing around and not taking the first answer. Keep probing people until you know you're on the right track.

I emailed someone from my company who heads up research on technology and medicine... He gave me a little bit of hope, a little bit of clarity.

If you are isolated at the start and there is a lack of support services, it becomes terribly pattern-forming. If you've never been to a support group before, you don't realise the benefit.



TIPS FOR FINDING INFORMATION

For information about cerebral palsy and other neurological conditions, visit www.cerebralpalsy.org.au. CPA can also provide a '0-2 dosage guide', which can give you more information about what may be required in terms of therapy.

There are some excellent Australian and international websites with easy-to-understand information about specific disabilities.

Disability-specific or local Facebook groups are a good source of information and support, particularly for immediate questions and concerns.

Parent blogs and video blogs can also be a great source of information and inspiration, especially on topics like food, equipment or travel.

There are a number of special needs publishers and online bookstores – more details on page 54.

Your local National Disability Insurance Scheme (NDIS) Early Childhood Early Intervention (ECEI) partner will be able to answer a lot of your questions. Visit www.ndis.gov.au/contact/locations. For more information on the NDIS, please see page 55.

More details and links can be found in the Resources section on page 51.



TIPS FOR FINDING SERVICES

Ask for a recommendation and referral to a disability service through your paediatrician, GP, or child and family health centre.

CPA can provide a guide on finding suitable providers. Visit www.cerebralpalsy.org.au.

The Raising Children website has a disability services pathfinder tool: www.raisingchildren.net.au.

Most local councils have a community directory of local services.

Ask other parents via Facebook or through community-based networks like the Australian Breastfeeding Association, playgroups, etc.

Ask for an interpreter if needed.

Note: Your child may be eligible to receive support through the NDIS. More details are at the end of this book (page 55). The NDIS website has a directory of all the registered service providers: visit www.ndis.gov.au.

Some parents benefit from counselling and being able to talk through their experiences. Speak with your healthcare team or your local GP about options in your area. Carers NSW also offer several support options at www.carersnsw.org.au/advice/talk-things-over.

Learn to trust yourself. Do follow your instincts, do listen to experienced professionals with whom you have built rapport. Do remember that at the end of the day it is your child, your family, your life.

Working with healthcare professionals and disability services

Parents have identified mixed success and satisfaction levels in their experiences with health professionals and disability services. Some find the right ones straight away, while others try a number before building a team that works for their child and family.

Doctors and other health professionals may not seem empathetic and often use medical jargon, and people from non-English speaking backgrounds and different cultures may lack the language skills and confidence to approach services and request assistance.

Parents often find they become more confident and skilled at expressing their child's needs and issues as the child grows older.

The core message from parents is 'trust your instincts' and try different services until you find one that works best for your child and your family.

PARENTS SAY...
Follow your instincts

SOME HEALTHCARE PROFESSIONALS ARE HUGEY SUPPORTIVE

We were emotionally and physically drained in the beginning. I couldn't formulate my sentences very well. My brain was scrambled. The nurse offered to make a list of anything that was going through my mind, any questions, before the rounds. I said, 'That would be amazing.'

She's always got time for you when you call and you're freaking out. Like we've always used 'hemi' and then we were thrown 'quad.' It was like, 'Whoa, whoa, whoa,' so I rang one day and she was amazing.

To have that relationship, where your therapist really cares about what your child is doing – the fact that they are seeing progress because you are putting the work in. You get more out of your therapist, as well. It is a two-way street.

My experience with professionals was generally positive and comfortable. I felt safe with the services. I had confidence in them. I had more information to take care of my child and to control his behaviour positively. I've learnt to relax through the material I was given that helped me to have less stress.



“We can’t just be parents. We’ve got to be advocates for these kids and it’s challenging.”

SOME HEALTHCARE PROFESSIONALS ARE LESS SUPPORTIVE

Our worst moment was when the paediatrician said she would be severely physically and mentally disabled, and the picture was very bleak. You are left with very little hope, and you always need that hope. He has been proved wrong I think, because my daughter is up now and walking and a little delight. Finding good doctors is mainly trial and error.

I remember doing therapy one day and just starting to cry. It was probably PMT as well. It was just getting really hard. One of the therapists said to me, ‘Are you still crying? Will you get over it?!’ It made me so mad. I never forgot it. She was a really nice girl, but I thought, ‘How dare you? This is my child! You have no idea how I’m feeling.’

Being first-time parents, we were very naïve and very scared. I’ve found over the years that some of the medical fraternity can be absolutely atrocious. Their bedside manner and basic humanity is just to be deplored. It’s awful. The other thing I have found is to not always trust what you hear in hospitals. Don’t be made to feel that you are just neurotic and over-concerned.

I’ve had good relations with the therapists. I have had problems with doctors’ lack of communication skills. I think it should be part of their studies to communicate. If they choose to work with children, they should learn how to treat them and their parents. I have had a lot of doctors and most of them do not have that skill.

One therapist we went to was very ‘old school.’ I don’t think she had updated her knowledge for at least 20 years. We didn’t stay with her for long. I thought there was no point. It’s time, money and effort.

OVERALL, EXPERIENCES OF HEALTHCARE PROFESSIONALS CAN BE MIXED

I’ve had some good and some bad experiences with professionals. It depends on their experience and insight into disability.

I’ve had some really positive experiences with professionals and some really negative. There are always wonderful people... Wonderful therapists, wonderful doctors and teachers. It’s basically the luck of the draw.

It was just pot-luck with his paediatrician... She had a really good bedside manner. Some of them can just be, ‘Oh, disability – the medical condition’, not ‘The child is a person’. But she’s fantastic.

IT IS OKAY TO TRY DIFFERENT SERVICES

When you’re in contact with other mums, you find people are trying all different things. Some of them will be seeing private therapists as well, just to compare. We’ve all tried it, just to see if there is any difference. There isn’t any difference.

You try different doctors and you travel all over the city. You go to this hospital and that hospital and you try everything. So I guess we’re doing as much as we can. I think at the end of the day it’s just a job for the doctors, whereas you’re always thinking, ‘What can I do better?’

PARENTS KNOW THEIR CHILD BEST

Do what you think is right and give everything a go. Not everything works for everyone. Trust your instincts and fight for what you want for your child. Don’t be shy, don’t take a back seat and don’t worry. Don’t think that someone is going to think less of you.

I think you learn to be tougher with health professionals and stronger and just don’t wait around. Now if I think of something, or I want to try this or that, I get onto them. As a parent, you know your child. You have to go with your instincts. I guess it’s confidence-building in a sense. I used to be this really weak person, but for his sake I had to be stronger.

For the first few years, I just did what I was told. I left it all in the hands of professionals and took every word as gospel. But I soon changed. They are only human as well. We basically knew what was best for our family. I started getting a bit stronger and questioned the professionals, services and everything.

I’ve been really lucky. We have five specialists and I haven’t had a bad experience with them. You often hear people who get pushed around but I’ve never let myself do that.

I have stood up to teachers on occasions. I didn’t think I would have the guts, but you have to be comfortable with what they recommend as well. There is a huge chunk of people that will slip through that if they are not from an English-speaking background or not very confident – I think they are the people that need the support.

Question everything. Do lots of research, although I guess at that time it’s really difficult. You don’t have the strength. The neonatologist said to us, ‘Stop being doctors and start being parents’, but they weren’t telling us the answers that we wanted to know. Even now, we are still researching. We can’t just be parents. We’ve got to be advocates for these kids and it’s challenging.



TIPS FOR WORKING WITH HEALTH PROFESSIONALS AND DISABILITY SERVICES

You know your child best – trust your instincts about the services that will best help your child and the way that you think they should be provided.



You have a right to full information. If you don't understand something, ask the professionals to explain it again.

Always get copies of reports sent to you and start your own file.

Think about your questions and write them out before you visit the service.

Take your partner, family member or friend to the appointment as a support person and to compare notes afterwards.



Find an advocate among your medical or health team. They will interpret the jargon, help you make sense of things, ask questions on your behalf, go into bat for you.

If you're not happy with a doctor or therapist look around or request another.

Don't be surprised if your GP or other mainstream health professional does not know much about your child's disability. Sometimes you have to find a guide and take it to them.

Know when you have done all you can, and rest.

Acknowledge your child's achievements. Take a moment from time to time to realise how you have grown and how much you have helped your special child.

PART 4

Childcare, Preschool and School



"The support I'm getting from the school is fantastic. I have a meeting with the principal at least three times a year to look at his progress. They've provided an aide for my son now."

Decisions, decisions

There are a large number of important decisions that have to be made in your child's first five years. Thinking about child care, preschool and school is fraught with anxiety and uncertainty for many parents. A question heavy on the minds of many parents of children with disabilities is whether they will be able to provide the same stimuli and care that the child has received at home.

The first decision for school is mainstream or special, public or private? Which alternative is the right one for your child? If it's a mainstream school, will your child receive the aid and support they need in the classroom? Will they be able to physically access all necessary parts of the school? How will they be included in all activities? How will other kids treat them? How receptive will the school be to your child's needs? How will they keep you informed of their progress or any issues?

PARENTS SAY...
These can be difficult but important decisions

MANY PARENTS SPEND A LOT OF TIME ON THESE DECISIONS

Choosing school was difficult – either physical disability, intellectual disability or mainstream school? There were issues at the school in relation to ramps and access to classrooms. I had to challenge the system.

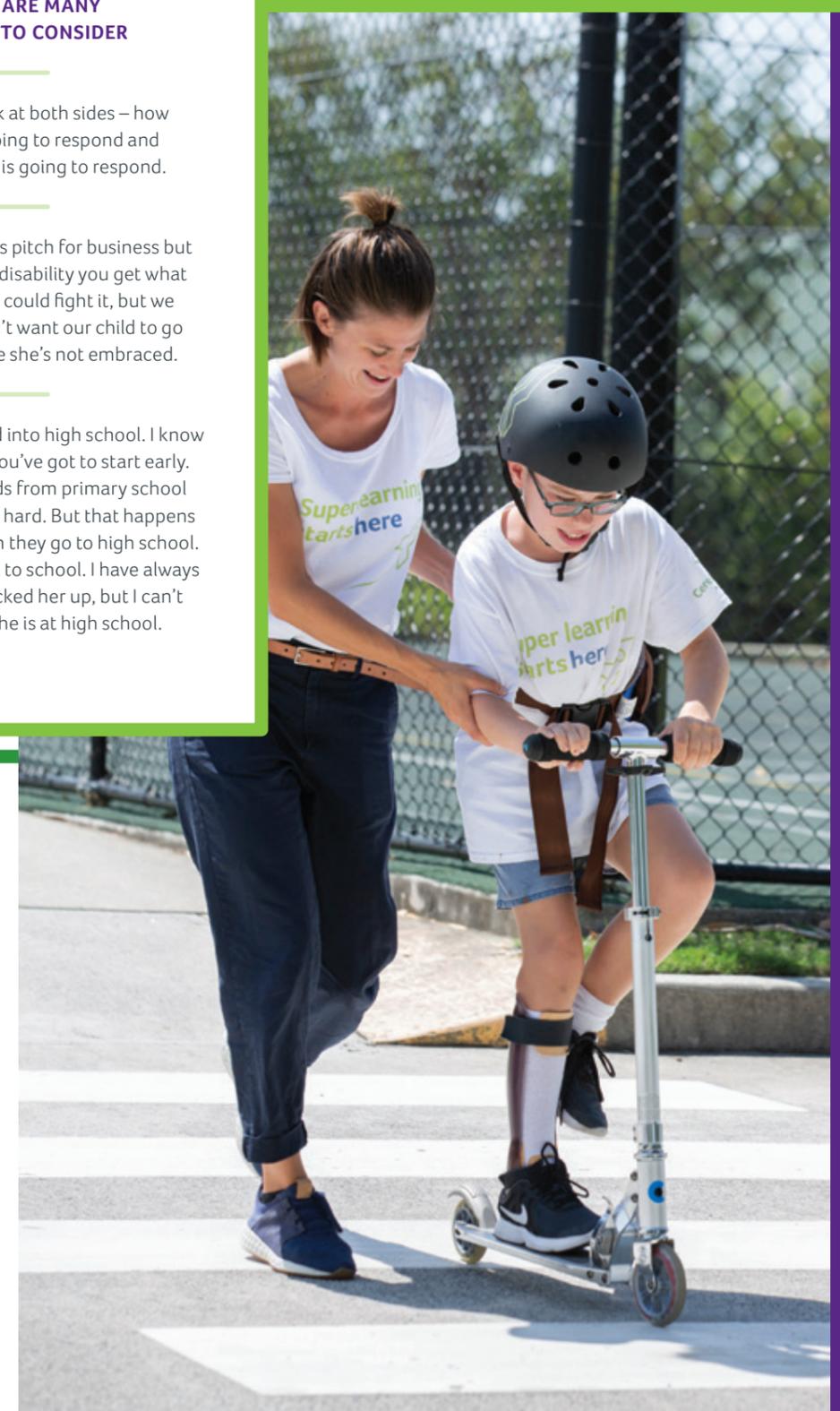
Maybe I place too much emphasis on everything – trying to get the most perfect place for her. It has been a difficult process and taken me months and months. I am happy with the decision now.

THERE ARE MANY FACTORS TO CONSIDER

You have to look at both sides – how your child is going to respond and how the school is going to respond.

The private schools pitch for business but if your child has a disability you get what you're given. We could fight it, but we thought – we don't want our child to go to a school where she's not embraced.

We have her booked into high school. I know from experience you've got to start early. None of her friends from primary school will go. That will be hard. But that happens to a lot of kids when they go to high school. She will catch a taxi to school. I have always driven her and picked her up, but I can't do that when she is at high school.



THE RIGHT SCHOOL CAN BE VERY SUPPORTIVE

The principal of the public school was very good with the transition from pre-school to school. She saw him in the preschool and did everything in her power to make him feel the same as the other kids.

Our preschool experience was stressful. Nobody understood my son and his needs. School is great. He is at a special needs school. They understand him. They know my concerns and they always let me know if there is a problem. I have given them full control, which takes a lot off my shoulders.

The support I'm getting from the school is fantastic. I have a meeting with the principal at least three times a year to look at his progress. They've provided an aide for my son now.

The local school was really great; they were fantastic. They said that my daughter is a member of this community and she deserves to go to her local school. They said she won't be a problem for the teachers and that the community will benefit from having her at the school.

I was lucky that he was in a local public school and the principal had an awareness of children with disabilities. There was support from other parents – I'm not saying all the time, but some. I think once a school has a person with a disability, the whole school should know about the condition – respect and accept the child and teach the other children to be accepting. It's good for them.

His teacher said, 'We have days where he's learning absolutely everything. Other days we know that it's not even sinking in. We just go with it. We teach him what we can and encourage the things that he's good at'.

The mums at the school have been a wonderful support. We haven't told all of the kids that my son has cerebral palsy, they've just made their child aware and compassionate of others. I feel like they've got my back. Helping me look out for him while I'm not there.

It's lovely, when we arrive in the morning there will always be a group of friends who rush up to greet him.

KNOW THAT IT IS OKAY TO NOT ALWAYS MAKE THE PERFECT CHOICE

After her diagnosis I started looking at schools. I visited about 15 schools and checked out the basic geography, what they had to offer, the type of personalities in the school and where I would feel comfortable leaving my daughter. It is a tricky thing because one of the main factors is her peers, which is out of my control. We will see how she goes next year. I guess it is not set in stone. If she doesn't cope with that environment, she can always change.

The preschool was very happy to take my son. They'd had kids with disabilities there before. But they weren't particularly good at listening to our concerns and opinions. Quite often you felt like you were being rushed out of the gate. A lot of the time we found that they were underestimating the level of care required.

We opted out of that school in the long run. It was making us miserable and we weren't satisfied. Then we heard about another school and their reputation. It was the most wonderful experience; for him and us, as parents. The staff were bright, cheerful and very supportive. They had time to listen to our concerns. They treated us like the experts. We couldn't have picked a better place for him to go.

I have mixed feelings about her school. One day I feel like she's in the best place ever and the next day I feel she's not.

HELP IS AVAILABLE

When I started looking at preschools I got in contact with our early childhood worker. We talked about what kind of things we need to do in the lead up and what you need to look for.

"I think once a school has a person with a disability, the whole school should know about the condition – respect and accept the child and teach the other children to be accepting. It's good for them."



TIPS FOR CHOOSING CHILD CARE, PRESCHOOL AND SCHOOL

Visit www.ecia.org.au/Transition-to-School for some useful information from Early Childhood Intervention Australia.

Talk to your NDIS ECEI team about the support available for the transition to a child care, preschool or school (see page 55 for more information about the NDIS).

Child care and preschools may have long waiting lists, so start early.

Start looking at schools when your child is two or three years of age. Mainstream schools can apply for funding to support a child with a disability but they often need a long lead-time. Seek advice from your therapy team on modifications your child might need and assessments to support the school's application for funding.

Visit a range of centres and schools. Meet with the directors/principals to assess how open, supportive and welcoming they are.

Take a list of questions. There's a good checklist at www.cerebralpalsy.org.au.

If it is a mainstream child care centre, preschool or school, ask if they have had experience with children who have additional needs. Do they have any specialist teachers? Can they access extra funding to support your child?

When transitioning to a new environment, take it as slowly as possible to reduce emotional and social stress, and establish a routine as early as possible.

Growing awareness during the school years



Children often begin to become more aware of some of the limitations imposed upon them by their disability when they begin school and realise there are activities that other children take for granted, but which for them may be difficult or impossible.

This is a time of challenging uncertainty, which may dent their self-esteem. The children may react by becoming angry, withdrawn or less cooperative with parents. Their reactions may be exacerbated if other children tease them in any way.

This can also be a difficult period for parents. Some of those who we spoke to said that they reflected their child's disappointments and sadness. Some experienced a sense of grief, of loss on behalf of their child. They also experienced a sense of loss regarding their own dream of their child's potential.

Others saw this time as an opportunity to identify their child's strengths and help them build upon these strengths.

PARENTS SAY...

The school years can be an emotional time

My child first became aware of differences when starting school and he realised he couldn't run as fast as the others, and then when he couldn't play soccer with the other kids. He loved soccer and really wanted to play but said, 'Mum, I'll only hold up the team'.

He would get very upset. Although he has difficulty expressing his feelings he would sometimes take out his frustrations on the rest of the family. He would cope by shutting himself in his room at home. At school he would cope by bending over backwards to offer help to the teachers whenever he could.

As parents, we looked for things that he is good at such as art and encouraged him. He is a determined kid. He had an opportunity to do a presentation to his class and he chose the topic of cerebral palsy. We encourage these opportunities to build his self-confidence. We are lucky in that he does not get teased at school.

She has always known what cerebral palsy is. She knows it is brain damage and that she is just special. She has gone through stages. When she was in about Year Two she cried herself to sleep every night and would say, 'Why did God make me like this?' She said, 'I look at people and watch them run Mum, and I think, oh I wish I could do that'. That would break my heart but she got over that and I believe that's just something that kids do as they grow and apparently they come to about 12 or 13 and it becomes a bit rough again – starting high school and hormones. I guess it's just the normal transitions that kids make. I think they always find it tricky no matter what.

When he was little I would help him with everything and so he didn't notice what he couldn't do. We never made mention of his disability or that he was different. When he was about six years old he started to notice that he couldn't do things but he still had the confidence to be happy. By about eight years he knew that he was different and that he couldn't keep up and do all the things that others his age could do. He got angry. I tried to help him to explain his disability to others – how it affected his leg and about cerebral palsy. At eight years his self-esteem was very low, it was like someone kept hammering him down. I tried to help him with his confidence, pointing out all the positive things. He has some very positive characteristics and I think sometimes he handles other people's attitudes better than me.

He became aware of differences when he started school. Some kids started calling him names like dumb because he has a slight intellectual disability. Also, when he could not join in certain activities and was excluded from birthday parties. He tended to retreat to his bedroom and listen to his music.

We started talking to him about his disability around the time we became involved in the parent support group. We talked to him about why he had so many doctors' appointments and explained in simple terms what cerebral palsy was. We answered his questions about medication. He is now in a class where there are other children with disabilities and he doesn't tend to feel so different now.

The critical period was when she was starting school, so around five years. Before that she was at preschool. Everyone knew her and they were all just together. We knew that going to a big school would be different. About six months before she started we talked to her about how she would tell other children about the disability, about the problems with the muscles in her legs. We tried to prepare her for the questions so that they wouldn't be unexpected.

“We never made mention of his disability or that he was different. When he was about six years old he started to notice that he couldn't do things but he still had the confidence to be happy.”

What parents recommend based on their experiences...

- Focus on the person – your child’s strengths. Look at the positive rather than the negative. My son is very loving
- Do what you have to now, so that you don’t look back in ten years and say what if, or if only...
- Look at what is important for the child. Start intervention as early as you can and follow the programs they set for home
- Acknowledge your child’s achievements. Take a moment from time to time to realise how you have grown and how much you have helped your special child to learn
- Pick up your child and show them the beautiful things in the world even if it is a spider web with dew on it. Encourage their aunts, uncles and grandparents to do this too
- Praise them for their effort. Share their milestones and achievements with family and friends
- No matter how severe your child’s disability, make sure they are treated in an age appropriate way
- Give them a wheelchair or other mobility device early if they need it. The longer they are left in a baby pram, the longer they are treated and talked to as such
- Don’t always jump in to defend or protect your child. Check before offering advice and respect what they want. We have to let them grow and experience the consequences of their actions. That is how they learn
- Never underestimate your child’s potential. Allow them, encourage them, expect them to develop to the best of their abilities
- Know when your child needs a break – don’t forget they’re only a child
- If your child is struggling emotionally, counselling can be a huge help. Talk to your GP about what is available.



TIPS FOR HANDLING YOUR CHILD’S GROWING AWARENESS

Some parents may feel a little awkward, but others have found that the situation presents an opportunity to talk to their child about their disability for the first time. You may find this helpful for both yourself and your child. It could also open up the possibility of future discussions.

Speak to your child openly and use the correct terms in a matter-of-fact way from the outset. Your child will learn by watching and listening to you. It gives them the knowledge and the words, but also a positive and confident attitude.

Develop some answers they can use for frequently-asked questions or comments. Rehearse them in a fun way at home, so they gain the confidence to say them in public.

Encourage your child’s resilience and resourcefulness. Helping your child develop positive ways to handle these disappointments will build their self-esteem.

Help your child identify the things that they can do and then encourage them to develop these skills and abilities further. This will bring them positive recognition and also build their self-esteem.

If your child needs extra support to work through their emotions, speak with your local GP or your healthcare team.

PART 5

Resources



Websites



CEREBRAL PALSY ALLIANCE (CPA)

www.cerebralpalsy.org.au

CPA is a leading provider of early intervention, family-centred therapies, life skills programs, equipment and support for people living with disability and their families. Visit the website for more information about these services and a range of conditions affecting the brain and muscles.

ASSOCIATION FOR CHILDREN WITH A DISABILITY

www.acd.org.au

An information, support and advocacy organisation for children with a disability and their families, based in Victoria. Their website includes resources to help your child and the wider family during the early years through to the teenage years, including advice on schooling.

AUTISM AWARENESS AUSTRALIA

www.autismawareness.com.au

Autism Awareness Australia works to improve the lives of all Australians on the autism spectrum and their families through the provision of quality information, targeted education and support for inclusion.

CARERS AUSTRALIA

www.carersaustralia.com.au

Carers Australia represents the needs and interests of people providing support to family members who have a disability, chronic illness, or who are frail or aged. State branches offer support (including counselling) and an extensive range of useful information.

CEREBRAL PALSY

In addition to www.cerebralpalsy.org.au, you may want to access:

- Australian Cerebral Palsy Register: www.cpreregister.com
- CanChild (Canada): www.canchild.ca
- CDC: Cerebral Palsy: www.cdc.gov/ncbddd/cp
- Cerebral Palsy Now: www.cpnnowfoundation.org
- NINDS: Cerebral Palsy: www.ninds.nih.gov/Disorders/All-Disorders/Cerebral-Palsy-Information-Page
- World Cerebral Palsy Day: www.worldcpday.org

EARLY CHILDHOOD INTERVENTION AUSTRALIA (ECIA)

www.ecia.org.au

ECIA provides a range of resources around early intervention, including information to assist in key stages, such as transitioning to school.

NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

www.ndis.gov.au

Visit the NDIS website for information on eligibility and access. See page 55 for more information on the NDIS.

RARE VOICES AUSTRALIA

www.rarevoices.org.au

Rare Voices Australia is Australia's peak organisation for rare disease, advocating for Australians living with rare disease. Visit their website for helpful information, news and events.

SIBLINGS AUSTRALIA

www.siblingsaustralia.org.au

Siblings Australia works to increase awareness of the needs of siblings of children and adults with a disability through information, education and by facilitating opportunities for siblings to connect with one another.

Facebook groups



RECOMMENDED BY PARENTS

- Adults with Cerebral Palsy Advising Parents of Kids with CP (closed group): www.facebook.com/groups/315904545214341
- Autism Parents Australia (closed group): www.facebook.com/groups/autismparentsaustralia
- Cerebral Palsy Parents Australia (closed group): www.facebook.com/groups/Cpparentsaustralia
- HemiHelp (closed group): www.facebook.com/groups/5512952137
- Hope for HIE (hypoxic ischemic encephalopathy) Australia (closed group): www.facebook.com/groups/hopeforhieaustralia



Books



There are many books available for parents with children who have disabilities or developmental delays, and for the children themselves. Try searching online, or have a look through the suggestions below.

SPECIALIST BOOKSELLERS AND PUBLISHERS

- Bilby Publishing: www.bilby.net
- Brookes Publishing Co: www.brookespublishing.com
- Little Parachutes: www.littleparachutes.com
- Silvereye: www.silvereye.com.au
- Special Stories Publishing: www.specialstories.net
- Woodbine House: www.woodbinehouse.com

BOOKS FOR PARENTS

Amelia & Me: On deafness, autism and parenting by the seat of my pants

Melinda Hildebrandt. USA: Agincourt Publishing, 2017

The powerful story of a mother facing the many ups and downs of raising her daughter, Amelia, who is deaf and has autism spectrum disorder.

Cerebral Palsy: From Diagnosis to Adult Life

Peter Rosenbaum and Lewis Rosenbloom. London: MacKeith Press, 2012

An easy-to-read book written by two of the world's leading clinicians in the field of cerebral palsy. It covers both the clinical side of cerebral palsy and what parents can do to promote their child's development and independence as they grow into adult life.

The Cerebral Palsy Toolkit: From Diagnosis to Understanding
CP Now: USA, 2015

A resource by and for parents of children with cerebral palsy. It guides readers through the initial diagnosis period, and provides other helpful resources and information about the different approaches to treating and managing CP. Available free to download from www.cpnwfoundation.org when subscribing to the mailing list.

BOOKS FOR CHILDREN

I Have Cerebral Palsy

Mary Beth Springer. USA: Star Bright Books, 2016

Meet Sydney, who likes the same things as other kids but also has cerebral palsy, which makes walking, talking and using her hands difficult. Readers can learn about the different items that make life easier for Sydney.

My Friend Suhana: A Story of Friendship and Cerebral Palsy

Shaila Abdullah and Aanyah Abdullah. USA: Loving Healing Press, 2014

A heart-warming tale of a little girl who forms a close bond with a friend who has cerebral palsy. The girl finds that, through her art, she can reach her special friend Suhana.

Best Friends: A Pop-Up Book

Sheri Safran and Mark Chambers. UK: Tango Books, 2011

A boy in a wheelchair and his best friend pretend they're pirates on a ship, mountain climbers, astronauts, explorers and Olympic sprinters. But even when they're not playing make-believe, they have a great time together doing everyday things – swimming and basketball – because they're best friends.

REAL LIFE STORIES

Visit www.cerebralpalsy.org.au/news-stories/real-life-stories for real-life stories from other families who may have experienced similar situations to yours.

PART 6

NDIS



When your child is diagnosed with a disability, a health professional is likely to recommend early intervention, specialised therapy and/or special aids and equipment. Your family may also benefit from extra help, time-out, counselling or someone to organise services.

The National Disability Insurance Scheme (NDIS) is a new way of providing support for all eligible children and adults with permanent and significant disability, their families and their carers in Australia.

If you are eligible for the NDIS, you will receive funding on an annual basis to purchase the supports, services, aids and equipment that your child needs.

These needs are assessed in a planning and assessment process managed by the National Disability Insurance Agency (NDIA). Your local ECEI partner can help you get started with your NDIS planning and ensure you get the most from your child's plan: visit www.ndis.gov.au/understanding/families-and-carers/how-ecei-works-step-step-process.



ELIGIBILITY

People who meet the following criteria may be able to access the NDIS:

- Have a permanent and significant disability that affects their ability to take part in everyday activities or, for children under 6 years of age, have a developmental delay
- Are under 65 years of age when they first access the scheme
- Live in Australia and are an Australian citizen, or have a Permanent or Protected Special Category Visa.

MORE INFORMATION

For more information about the NDIS, visit www.ndis.gov.au. The NDIS website also has an Access Checklist tool to find out if you are eligible to receive assistance from the scheme.

CPA is a registered NDIS provider, with services for children and adults with a disability. Find out more at www.cerebralpalsy.org.au.

ABOUT FOLLOW YOUR INSTINCTS

Follow Your Instincts is a selection of honest and revealing insights from parents who have a child with a disability. Parents share their experiences of:

- Their child's birth
- Growing concerns
- Their child's diagnosis
- Breaking the news to family and friends
- Relationships
- Brothers and sisters
- Finding information and services
- Working with professionals
- Child care, preschool and school
- Their child's growing awareness.

Follow Your Instincts also features useful tips from parents, recommended websites and online groups, organisations and information resources.

“This is a must-read for every parent who has a child diagnosed with a disability.”

“Straight from the heart.”

“This is a wonderful book. Thank you for the opportunity to read and learn, I am sure many parents will benefit from it.”

“I'm relieved to see that other parents have gone through similar experiences and survived. There is a sense of belonging – that I am no longer on the outside. I'm so thankful that these parents have shared their experiences. It has given me confidence in my instincts, capabilities and coping skills.”

“This would also be helpful for grandparents to understand the emotional side and the need for support.”

“This book is great because you can truly relate to its content. It shows you are not alone and that a lot of the emotions that you go through are normal for the situation.”

“I loved it and cried a lot (which is a good thing). It is all relevant and important. I would love my family and friends to read it.”

ABOUT CPA

Cerebral Palsy Alliance (CPA) is a leading provider of early childhood intervention services throughout NSW and ACT, supporting children aged 0-6 years, and beyond, with a range of physical and neurological disabilities to achieve their goals.

Conditions we support include cerebral palsy, autism, global developmental delay, acquired brain injury, muscular dystrophies, stroke and genetic syndromes.

We work closely with our families to create a personalised and family-centred approach to suit every child's individual developmental needs.

Start your journey with us today and let us help your child become the person they're really meant to be.

FOR MORE INFORMATION, PLEASE GET IN TOUCH:

 Call us on **1300 888 378**

 Email us at **ask@cerebralpalsy.org.au**

 Visit **cerebralpalsy.org.au**



Cerebral Palsy
ALLIANCE