

# Diagnosis and adjustment

Finally, the medical fraternity confirms the words that a parent may have been dreading. 'Your child has a disability' or, 'Your child has cerebral palsy'.

For many parents cerebral palsy is an unknown condition. Following the diagnosis, doctors may provide either too much technical information, or not enough.

For other parents it is a relief. At last they know and can now seek out support from disability services. Still other parents experience disbelief, shock and guilt. 'Why has this happened to me? Did I do something wrong during the pregnancy? Am I being punished? Are the doctors at fault?'

For most parents, the diagnosis appears to happen around 8-18 months, when developmental stages can be more thoroughly examined and accurate assessment made. It can be a very long wait. The confirmation of a disability is often conveyed to parents very casually. They may not be offered counselling support to help cope and process this information. It is often a devastating experience when they are left alone with their thoughts and their emotions.

Parents often feel a betrayal of trust when they realise that the health professionals suspected their child had a disability, but did not say anything.

Questions about the future are in the minds of many parents. Will my baby walk, talk, how dependent on me will they be, what quality of life will they have? Grappling with medical terminology is another battle - athetoid, hemiplegia, microcephaly, and other jargon. There seems so much to understand with not nearly enough explanation by medical staff.

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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.

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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. So he was diagnosed.

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.

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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.

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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 OK. 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.

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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 hundred miles 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.

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My head was full of questions, 'How could it be?' and, 'How can she have that if she has been so well all along'. The problem we found out later, through MRIs... was that I had a flu virus at 15 weeks that crossed over and gave her the brain injury. I thought there would be more medical issues at this stage than there was.

The greatest fear, after cerebral palsy, was that my child would be institutionalised - my baby was going to be taken away from me. I am a health professional, but I still thought my baby wasn't going to be my baby anymore. She was going to be a child that was taken into care and looked after and fed and clothed by the state or something. Second was the fear that she may also have an intellectual disability. 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 they would relate to her? The impact that it would have on the family and on my husband.

*Editor's note: Readers are reminded that over the past two decades there has been a significant movement away from institutionalisation for infants and children with disabilities. Whilst this might still be an understandable fear in parents' minds, policy and practice has now shifted firmly to providing a range of support so that children can remain in their own families and communities.*

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You hope that everything will be OK. I was actually keeping in touch with another couple from the hospital. They had twins. My son, with his milestones, was doing the same things as one of their children and she was fine at the hospital. But when we went back for our one year corrected check at the hospital, they said he had cerebral palsy.

So you get over having a preemie and going through all that and then you kinda 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.



I found it 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.

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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 one 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.

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I had him at 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. They wanted me to see a paediatrician and then decided - no - to wait for the neurologist. They had obviously written him a letter saying they thought my son had CP. Because they couldn't tell me, they sort of 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 CP. It wasn't until my son was seven months old that the doctor said he definitely had CP. I said, 'What?!' So that was a bit of a shock.

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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'.

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**Never let anyone tell you not to cry  
because it is a grieving process**


She was diagnosed at about nine months, including three months prem. The doctors, the paediatrician, had never said anything to me at all... and 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. They don't like to say anything until the child is about one.

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 that's why things are like this and she would get better as she grows.

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?' Of course, then you always want something more as you go along. It's really awful at the beginning because you don't know what the future holds. In a way I wanted to turn the clock forward so I could see what the future had in store for her. I would see how good she'd be or how bad she'd be. Christmas was really awful when she was little... like the kids on bicycles. I just cried. I'd just think my daughter is never going to do that. But you get over that. That's just at the beginning I think.

You have to accept. You have to accept and also you can cry and cry and cry your little heart out. Never let anyone tell you not to cry because it is a grieving process. It is like a death. I used to hang the clothes on the line and cry my eyes out and I was under depression. But you have to go through that. It's like someone has died. I completely agree that it is a grieving process. Every child is different and every parent is different. Their acceptance and tolerance are different as well. I've been speaking to some other parents and I'd say ten years down the track they are still not over it. They still have a hard time accepting that this has happened.

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The doctor knew my son was born with these problems and he said everything seemed fine with my daughter. So I was happy and thankful... with the precautions we had taken. But one day I went to feed her in the hospital at midday and the doctor was there, waiting for me. I knew something was wrong. He wouldn't speak to me. He said he wanted to see us together. So my husband and I went in. The doctor said that the test showed two white patches in the lower part of the brain and that meant my daughter might - he didn't say she will, but she might - have the same problem as my son. What could we say? Nothing. I just sat there stunned.

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When I went to see the specialist he just told me bluntly that my son had cerebral palsy... So I went straight home and said to my husband that our son has cerebral palsy and he said, 'What! He doesn't have cerebral palsy?!'

I said to the doctor, 'Why didn't you tell us before?' I didn't know what to do, because I didn't know much about cerebral palsy. You have to find out, which is what I've done. I wanted to learn more about cerebral palsy and why it happened and what we can do for these kids. I don't care about what happens to me. I walk, I talk, I can do anything. I wanted him to be as normal as possible. Any question we ask they say, 'We don't know.' So I don't ask these questions anymore and just try to do what I think is good.

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The diagnosis was indeterminate for probably about 14 days. It turned out to be a rare condition, which is one in 50,000. It was a bit of a process of elimination. So that was the start of it all.

We were kept in the dark about a lot of it because either they didn't think we would understand, or it was a need to know basis. We found that kind of thing very, very hard to deal with. We had been moved to a ward with six other kids when our son was actually diagnosed .... We were told his diagnosis, and a very short prognosis that he was going to be severely affected - brain damaged and physically handicapped - 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. That was a bit discouraging to say the least.

I think one thing that struck me all along - there is never any picture painted at the prenatal classes. You don't want to go scaring people, but there is never any second scenario painted. 'Everything is fine. You'll have beautiful babies'. All the funny stories and that sort of stuff. There is never anything mentioned about the possibility. Those sorts of things could be touched on in the very early stages. After it was over we sat back and thought, 'Nobody ever mentioned that anything could ever go wrong'. You sort of hear about it but it is the sort of "it could not happen to me factor".

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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 naive 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.\* It could be just seizures, it could be intellectual, it could be physical. It varies in each child.

They were still in intensive care so we carried on. I was there between 6am until midnight every day. Then my second child was diagnosed. They didn't tell me the day he was head-scanned. I happened to bump into the neonatologist as he was leaving and he said, 'Did the doctors tell you yesterday about your child's head-scan?' I said, 'No. I had no idea that he had one'. I was by myself that night because my husband was at Uni. The doctor said that my second child had PVL as well. I said, 'No, this is just a joke'. I barely made it home driving. I don't know where I was. I waited for my husband to get home about 10 or 11pm and it was just like, 'this can't be happening'.

We knew that two were diagnosed with PVL. Basically being premature babies it was hard to see the severity. I fed 'em and nursed 'em and bathed 'em. So small. I kept on questioning for the first few months. They were all reflux babies. [Then my third child started to show signs]... waking up in the middle of the night and stiffening his arm and arching. I said, 'Something's wrong with him, the other two aren't doing that'. The doctors were just saying, 'Oh, it's just his reflux, it's just his reflux'. He would just start screaming, bend his arm and arch himself in really weird positions. It wasn't until December that the doctor gave me a referral to see the neonatologist. He put my child on the table. He did a few stretches and said, 'Yes he's a spastic quadriplegic. Here's a script [for a muscle relaxant]. See you in six months'. I walked out and I thought, 'This is just not happening. Three out of three cannot have cerebral palsy'. I ripped the script up outside and threw it in the bin. I came home and it was just like 'totally don't know where we were'. So basically we carried on.

We went to the Health Centre and a movement specialist told us to talk to our doctor. He 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 10 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 we would be coming up with. This was so good and 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.

## Tips for doctors breaking the news ...

- No one likes to give bad news but don't expect parents to be sensitive to how you feel. Your discomfort, expressed perhaps through your body language or facial expression, may be interpreted as lack of compassion.
- Break the news gently; consider the timing and the setting. Allow privacy, and time up follow up discussion day or so later.
- Don't underestimate your impact. How you give the news, the tone you use and the language, is likely to be what parents say to grandparents, relatives and friends.
- Be clear and truthful. Bland and generalised reassurances are usually not helpful.
- Give hope. Explain specifically what can be done to assist the child's progress/development.
- Model your acceptance. Holding the child whilst you break the news and using the child's name can give parents a strong message that you value their child.
- Allow parents the dignity of disbelieving you. Denial can be a healthy response in the early stages. Even parents who can accept intellectually the facts as you deliver them will often hold on to hope of a miracle. Remember that the head and the heart don't always need to connect.

\* PVL - Periventricular Leukomalacia - see definition page 47