



# New Families - Getting the News

## The diagnosis

You have just been told that your child has cerebral palsy.

When you find out your child has cerebral palsy you may find that it leaves you feeling overwhelmed. You may experience shock, anger, resentfulness, or just sadness. These are all typical responses. You can't change your feelings and there is no right way to feel about these things.

## Getting the news

### How did you get the news?

A diagnosis of cerebral palsy can be delivered at different times. When your baby was born, the doctor may have told you that your baby suffered some brain damage. Or maybe a health professional spoke directly to you stating that your child has cerebral palsy. It may be that a friend or family member mentioned some differences with your child or a health worker has slipped out some information in an unexpected way. You may be currently awaiting a diagnosis.

Whatever way you get the news, it can be a confronting and traumatic time. Some people prefer to hear the information in one hit and others prefer to receive small bits of information over time. The reality is however that the way the news is given is often not as you may have wanted.

## Your feelings

- Most people need time to absorb this new information and the opportunity to observe and process it for themselves.
- You might feel numbed by the news and feel you are interacting in the world but you feel like the world is also passing you by.
- You might find that it is hard to believe the information presented to you. You could find yourself thinking, 'I'll wait and see for myself'.
- You might feel very sad and finding it hard to feel hopeful about the future.
- Some people feel angry and upset, and often you just want to yell at anyone and everyone!
- You may even feel relieved to be given the diagnosis because you may have been worrying about why your child's development was progressing differently to other children.
- Often getting the news can help parents to mobilise their energy to moving forward and working out what is to be done next.

## Why do I feel the way I do?

### Sadness

Being around other families with children of similar ages to your child is often the environment for sadness to be triggered. You might notice that as you observe other children doing what your child struggles to do, strong emotions are provoked.



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## Worry

When the diagnosis of cerebral palsy is received it can create feelings of worry. 'What did I or my partner do during pregnancy? 'Did I/she eat the wrong things, did I/she not rest enough, or did I/she do too much exercise?' These are common questions you may ask yourself.

If you are struggling with worries it can become a very difficult emotion to contain and it can take energy away from your ability to care for your baby. If these feelings become dominating, seeking support is definitely an important step to take. Specialist support services are available and have experience and understanding of the issues confronting families of children with cerebral palsy.

## Anger

You may find that you feel very angry and resentful. You may have anger directed towards the medical staff that attended you through your pregnancy or birth. You might find that you feel angry that no one has been honest with you and given you clear information before now. You may feel angry about the way the diagnosis was given to you. You may just feel angry but don't really know what about. Whether there is a reason to feel angry due to medical intervention or there is no one to blame, anger is a normal reaction. Mobilising the anger into positive energy for your child is a big challenge yet many parents report finding extraordinary energy to deal with the diagnosis of cerebral palsy - often they discover internal resources that they didn't know they had.

## Love

No matter what everyone tells you about the implications and consequences of having a child with cerebral palsy, this child is your child. You may find that your love is fierce and protective. Some parents state that they didn't realise they had the capabilities for love in the way they love their child.

Positive feelings such as love and acceptance enable parents to move forward as they identify their hopes for their child and plan their future together.

## Family stories

### Martine

'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...you're in a movie...on the outside looking in.'

### Anna

'We went to the Health Centre and a movement specialist referred us to a paediatrician. The paediatrician was excellent. After he told us he left the room for 10 minutes so 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 we would be coming up with. This was so good and he was very positive about the things that were good, very enthusiastic about the things he thought she could do.'

### Jo

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

### Alicia

It took a 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.



## The search for answers

### A million questions

You may want to ask a million questions! Whatever the amount and nature of information you first receive it is normal to want to get more information...a second opinion...to talk it through, to try and understand all the implications of a diagnosis of cerebral palsy. Typical questions include how will my child be affected, what types or categories of cerebral palsy are there, will my child's condition get progressively worse, is there a cure, are there any other side effects with cerebral palsy?

There are many places where you can access this information but your health professionals are a good resource as well as specialist organisations, like The Spastic Centre.

### How does a child get cerebral palsy?

The first question that often comes to mind on hearing the diagnosis of cerebral palsy is 'how did this happen?' The science behind understanding cerebral palsy is continuing to be investigated. Doctors consistently tell us there is not a clear answer on these questions. Cerebral palsy occurs due to an injury in the brain. It develops mostly during pregnancy, occasionally at birth, but for the most part doctors don't know why.

## Family stories

### Kim

At the birth when the doctor tells you that your son has brain damage you think its 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.

### Emma

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

