



INTRODUCTION

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

Today, I'm going to share some general information about cerebral palsy. You may be a parent who has a child just diagnosed with cerebral palsy, or you could be a grandparent whose grandchild has been diagnosed.

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

The important thing to remember is that no two children with cerebral palsy are alike and it's very hard in the early stages to predict what impact cerebral palsy will have and what the future holds.

So much can be done to support children with cerebral palsy and their families nowadays. Despite the initial shock, parents universally tell us that after a time, the personality of their child shines through and the fact that they have cerebral palsy becomes secondary.

There are many services out there to help you and your child - with early intervention, equipment and family support. Over time, you will meet many other parents and special individuals – who you may not have otherwise met – and these people will make the journey easier for you.

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So what exactly is cerebral palsy? It's a permanent physical condition that affects a person's ability to move and balance. It is caused by an injury to the developing brain, usually before birth. Some people with cerebral palsy are only mildly affected – they might just have a weakness in one hand. Others are much more profoundly affected – they may have almost no voluntary movement.

In Australia, there are approximately 33,000 people with cerebral palsy. Worldwide, the incidence of cerebral palsy is 1 in 400 births. For most people who have the condition, the cause is unknown and there is no known cure.

There are three main types of cerebral palsy and each involves the way a person moves. Movements can be unpredictable, muscles can be stiff or tight and in some cases people can have shaky movements or tremors.

There are also a number of physical and cognitive issues associated with cerebral palsy, which I'll discuss in more detail later.

Cerebral palsy, except in its mildest forms, can be seen in the first 12-18 months of life. It often presents when children fail to reach movement milestones. Babies most at risk of cerebral palsy are those born prematurely or with low birth weight. But the majority of children with cerebral palsy are born at full term.

Most people with cerebral palsy have a normal life expectancy.

TYPES OF CEREBRAL PALSY

There are three main types of cerebral palsy:

The first is called spastic cerebral palsy and it's the most common type, affecting 70-80% of people.

Spasticity means stiffness or tightness of muscles. The muscles are stiff because the message to the muscles is sent incorrectly through the damaged part of the brain.

When people move, some groups of muscles become tighter and some groups of muscles relax. In people with spastic cerebral palsy, both groups of muscles may become tighter. This makes movement difficult or even impossible.

The second type is called dyskinetic cerebral palsy, which affects about 10-20% of people with cerebral palsy.

There are two forms:

- Athetosis is characterised by uncontrolled, slow, 'stormy' movements;
- Dystonia is characterised by sustained or intermittent muscle contractions causing twisting or repetitive movement.

Finally, there's ataxic cerebral palsy.

This is the least common type of cerebral palsy and is characterised by shaky movements. It affects a person's balance and coordination.

Many people have signs of more than one of the three types. The most common mixed form includes spasticity and dystonic movements, but other combinations are also possible.

PARTS OF THE BODY AFFECTED BY CEREBRAL PALSY

The parts of the body affected by cerebral palsy differ from one person to another. Certain words are used to describe the parts affected:

Hemiplegia – means that the leg and arm on one side of a person's body are affected.

Diplegia – means that both legs are affected significantly more than the arms. Children with diplegia may have some clumsiness with their hand movements.

Quadriplegia – means that both arms and legs are affected. The muscles of the trunk, face and mouth may also be affected.

WHAT CAUSES CEREBRAL PALSY?

As I've mentioned, cerebral palsy results from damage to a part of the brain and for most people, the cause is unknown.

However, researchers have identified some risk factors for cerebral palsy. These include:

- Premature birth
- Low birth weight
- Blood clotting problems
- An inability of the placenta to provide the developing foetus with oxygen and nutrients
- RH or A-B-O blood type incompatibility between mother and infant
- Infection of the mother with German measles or other viral diseases in early pregnancy
- Bacterial infection of the mother, foetus or infant that directly or indirectly attacks the infant's central nervous system

- Prolonged loss of oxygen during the pregnancy or birthing process
- or, severe jaundice shortly after birth.

It is important to understand that even if a mother or infant does have any of these risk factors, it doesn't mean that the child will definitely get cerebral palsy. It just means that the chance of having a child with cerebral palsy is increased.

ISSUES ASSOCIATED WITH CEREBRAL PALSY

There can be a number of physical and cognitive issues associated with cerebral palsy. In addition to impairment of mobility, children may also have difficulties with speech, swallowing, saliva control, perception and sensation. They might have learning difficulties, issues with intellectual development, or behavioural or emotional problems. They could develop hip or spinal conditions. A smaller number may have vision or hearing impairment.

Cerebral palsy is very complex and it is unlikely that your child will experience all of these. Please remember that there are many interventions for these issues and many people who specialise in supporting children with cerebral palsy and their families. Your paediatrician or GP will refer you to the major cerebral palsy organisation in your area and they will help you work out the services and supports your child needs. Be reassured that your GP or paediatrician will also regularly re-assess your child, so that if any of the associated conditions present, then your child can be referred onto specialist therapists. They'll have the skills to help your child achieve the best possible outcomes.

CONCLUSION

Having a child with a disability usually comes as a complete shock and most parents have had no life experience that might have prepared them for this event.

In the early stages, you can be given a diagnosis that is difficult to understand and very different to your dreams and hopes for your child. But as your child grows, when you're all living in the moment, you'll see their happiness and zest for life emerge – and ultimately, that's what we all want for our children.

American author, Emily Perl Kingsley, likens having a child with a disability to making travel plans where you unexpectedly end up in a different place. She said, 'You expect to land in Italy and you end up in Holland'. But then she goes on to say how, even though you mourn the loss of Italy, you'll come to realise how beautiful and very special it is in Holland'.

Older parents overwhelmingly tell us that their advice for parents of a newly diagnosed child is, 'Follow Your Instincts' – go with your gut feelings about what is right for your child and your family.

They also say, 'Take one day at a time and take that day positively - and ALWAYS look at your child, not at the disability. It's very rewarding when your child achieves the goals that you may not, at first, have ever thought were possible.

CLOSE

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

You can download or listen to more episodes in the ParentWise Podcast series on the Cerebral Palsy Foundation's website.

The Cerebral Palsy Foundation raises money to fund research into cerebral palsy. Find our website at www.cpfoundation.org.au