



cerebral
palsy
scotland

Talking to my child about cerebral palsy

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Why is it important to talk to my child about cerebral palsy?

Help them to make sense of who they are

Talking to your child openly about their cerebral palsy diagnosis will help them to make sense of who they are and to understand their strengths, as well as the things that they find more difficult. This will also reassure them that they can come to you with any questions or worries about their disability.

When do I talk to them about cerebral palsy?

Talk about it as part of everyday conversation

If you try to give your child lots of information at once, it can be overwhelming for them (and for you). Instead, talking about your child's cerebral palsy as part of everyday conversation, and from a very young age, helps them to make sense of their disability and accept it – simply as part and parcel of who they are.

Follow your child's lead

Give your child little bits of information, in response to their questions, and on an ongoing basis, rather than sitting down and having a one-off discussion. There may also be times of the day, or different environments, when you know that your child finds it easier to talk and when you have more time to listen. For example, dinner time, when you are putting them to bed, or when it is quiet, might be good opportunities for a chat.

How do I talk to them about cerebral palsy?

Talk openly and honestly

Children benefit from adults speaking to them in an open, and honest way.

Stick to the facts when discussing your child's cerebral palsy. If you avoid talking about the difficult stuff, or minimise the things that they find hard, children will be very aware of this and will think that they 'don't have permission' to talk about these things. If children lack the information that they need to help them to make sense of their diagnosis, they are more likely to use their imagination and to come up with inaccurate information. This can be much more anxiety provoking for them than the truth.

How do I use the right approach for my child?

Tailor your approach to your child's age, stage, and understanding

Children will be confused by complex information that they can't understand. How you talk about your child's diagnosis will depend upon their age, their level of understanding and their developmental stage.

Younger children may ask questions more openly, and benefit from concrete language and examples that help them to understand their cerebral palsy. For example, with a child aged three to four, you might explain - and show them by touching or using pictures – that “The muscles in your legs are tight and that makes walking hard.”

For an older child, you may be able to use more abstract language. For example, you might explain to them that “their brain doesn't always send the right messages to their legs/arms”. Or, you may start to explain words such as ‘ataxic’ or ‘spastic.’ For example, “Spastic cerebral palsy means that your muscles feel tight or stiff.”

Change the way you communicate with them as they grow and develop

As children reach adolescence, they become more self-conscious and are more aware of others around them. They may not speak as openly about their cerebral palsy. It can be helpful to reassure them that you are always there to answer any questions that they may have and to talk through anything they are struggling with.

Consider your child's learning needs

If your child has a learning disability, how you discuss their cerebral palsy will depend upon their level of understanding and upon how they communicate their needs.

For example, for children with good understanding skills, but who are unable to communicate their needs well orally, you will need to minimise your language and supplement your words with visuals and gestures which show them different parts of the body, and how these work. For example, you might use visuals which depict ‘legs’ or ‘wheelchair’ or visuals and gestures to describe ‘tight legs’ or ‘legs which move a lot’. You will also need to allow them more time to process the information.

For children with a more significant learning difficulty who do not understand abstract language, it will not be possible to talk to them directly about their diagnosis. Instead, it may be more appropriate to use gestures and touch to indicate different parts of their body. For example, ‘arms, sore’, and how these might feel.

How can I help to develop my child's coping skills?

Focus on their strengths

Talk a lot about your child's strengths, and in response to the things that they do well. This will help to develop their feelings of self-competency.

Be specific about the praise you give. For example, instead of saying: "Wow that was amazing", say, "I was really proud of the way you stood up from your chair."

Work out with your child realistic targets that they want to focus on to increase their skills, such as making a sandwich, or brushing their teeth on their own.

Help them to talk about cerebral palsy to others

If children are struggling to answer other peoples' questions about their disability, it can be helpful to give them (or to practise with them) 'scripts' or set phrases which they can use.

For example, if someone asks them why they have a wheelchair, they may say: "I have cerebral palsy which means my muscles get very tight/are hard to control. This means that it takes me longer to move my arms/legs."

Help them to talk about cerebral palsy to others

It is normal for your child to become upset when they cannot do something because of their cerebral palsy. As a parent, it is natural for you to want to make it all ok again.

The hardest thing to do - but often the most helpful - is to sit with your child's feelings, and accept that it is hard, or unfair, or that they feel sad. For example, "It's frustrating that you have to have an adult to help you. It makes you angry. No wonder. What can we do together so that you find it a little easier?"

Validating your child's feelings by acknowledging them - rather than trying to 'fix it' - will mean that your child feels heard and understood. This will also make them feel safe. When a child feels supported in this way, it is easier for them to develop strategies which help them to cope the next time. This is the key to them developing resilience.

Getting further support

Cerebral Palsy Scotland is a charity that improves the lives of children and adults with cerebral palsy through specialist therapy, support and information.

For further help and information, visit cerebralpalsyScotland.org.uk, email info@cpscot.org.uk or call 0141 352 5000.



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