

# Parent to Parent



## Talking With Others About Your Child and CP

All parents of children with cerebral palsy (CP) remember the moment they learned the diagnosis. Whether it was shortly after birth or sometime after, once the diagnosis is applied a lifelong learning curve begins. One of the first and most challenging aspects of that learning curve is how to talk with others about your child's disability.

As parents of young adults (Dillard, age 21, and William, age 24), we want to share things we wish we had understood better when our children were young!

Keep it simple. Parents often learn a great deal about CP while consulting specialists and determining options for therapy. But caregivers, acquaintances, and parents of other children don't need medical information; it's fine to share the basics directly and factually.

"CP is caused by a brain injury; most likely it happened during William's birth."

Especially when responding to young children, give them answers in terms they understand.

Q: "What are those things in her ears?" A: "Hearing aids—they help her ears to hear better like glasses help eyes to see better."

Q: "Why can't he walk?" "What are those things on his legs?" A: "Dillard was born extremely early and was very sick, so he needs help with balance. His orthotics support his legs to be stronger."

If your child communicates directly, encourage him or her to take the lead.

"I need support with my balance because an area of my brain was injured when I was born. I have cerebral palsy; that's all."

The more matter-of-factly questions are answered, the better other people understand that CP is a fact of your child's life—a challenge, not a tragedy.

Emphasize the positive. When people hear the words "neurological injury" or "brain injury" they may assume CP is progressive or even life-threatening. It's helpful to say up front that CP is not a degenerative disorder such as ALS.

# Parent to Parent



“Once the brain injury happens, it's done—the brain injury doesn't get any worse.”

Help people understand that human development is a process. The consequences of CP may intensify as a child grows taller and heavier (e.g. spasticity may appear more severe, low tone in the torso may make it harder to sit upright). But it's a comfort to us, as well as others, to say how amazingly adaptable our brains are and that many children continue to gain skills into adulthood.

“Over time, it's likely that her brain will adapt and find ways to continually improve.”

Use person-first language. Let others know how to describe your child, i.e. a “child with disabilities” rather than “a disabled child.” It's more than political correctness. Person-first language reinforces that our kids do everything other kids do, just in unique ways.

Acknowledge how your child is specifically affected. Sometimes people try to compare the capabilities of one person with CP to another; they may also assume a child with motor disabilities also has intellectual disabilities. It's helpful to say that CP manifests in unique ways in each person, and spell out how your child functions.

“CP affects everyone differently. For William, it means he isn't walking yet and it helps him if you ask simple yes-or-no questions.”

“She has to work hard to sit up and use her computer, but she understands everything you say.”

Disability does not equal illness. When your child looks visibly different, people may assume that she is sick or medically fragile. If that is not the case, people are relieved to know for sure.

“She's perfectly healthy—she just needs extra time to crawl over to that ball.”

Suggest ways to promote your child's progress. An unspoken question may be, “How should I relate to this child?” Remind others that your child is a child first, and a child with disabilities second.

“Treat him like you would any child, and encourage your child to do the same.”

# Parent to Parent



“If you don't believe she can, then she won't—because you may not do the things that will help get her there. So believe she can and that will help her make progress.”

Model inclusive behavior. If people talk about your child in her presence as if she's not there, they need you to educate them out of excluding her. Show them how. For example, say your son has dropped a toy and the man in the store next to you starts to pick it up. You can demonstrate your child's independence.

“Oh, William can pick that up himself. William, pick it up please. But thank you so much for offering!”

If your child genuinely needs the help to retrieve the toy, involve him in the interaction.

“Oh, thank you so much. William, can you say thank you yourself to this man?”

Remember: all your communications about CP help build a more welcoming world. Of course, having a child with CP is exhausting and frustrating at times for our kids and for us; we don't always have the energy to educate other people about CP. However, it is an effort very much worth making. We are all working to prepare our children for the world; but we can also help prepare the world for them. Whenever we share the joy we have in our kids and our pride in their hard-won accomplishments, we are helping to create the fully inclusive world we want our kids to live in.

Written by Barbara Sieck Taylor and Paula Drew

Input from: Marquitha Gilbert, Lisa Diller, Nancy Ford, Tina Hjorngaard, and Kimberly Rayfield