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## 11 Things Parents With Children In Wheelchairs Have To Deal With

The Huffington Post Canada | By [Arti Patel](#) Posted: 04/03/2014 11:59 am EDT

Raising a child with a disability is a challenge in and of itself, and for parents who have to deal with insensitive questions, whispering or staring from strangers, it just adds to the stress.

[Marcy White](#), author of *The Boy Who Can: The Jacob Trossman Story*, shares a love story and survival guide of raising her 11-year-old son diagnosed with Pelizaeus-Merzbacher disease, a rare and incurable neurodegenerative disease, in her new book.

“When Jacob was born, doctors said that he would never speak, sit or eat independently,” she says. “They said he wouldn't understand what was going on around him or be able to learn.”

Despite this, Jacob and many other children like him go to school and use customized technologies like iPods to communicate with family and friends.



Marcy White

### *Marcy and Jacob*

But one thing White says she often has to deal with is strangers' rude remarks or people who are too afraid to talk to her child, and this is a common concern for parents of children with disabilities.

Huffington Post blogger Dr. Darla Clayton has written on this in the past, noting that people who tell a [parent their child "looks normal,"](#) or suggest ["they'll grow out of it,"](#) can come off as rude — even if it wasn't intentional. Clayton also followed up with a list of [conversation starters people try instead, without sounding like a complete jerk.](#)

But White says at the end of the day, being unintentionally insensitive or just ignorant always ends up hurting the child. "Don't forget that the person in the wheelchair is more than simply a body in a chair. He or she has thoughts and feelings," she says.

**Here are 11 things White says is common for parents with children in wheelchairs to hear or experience — and what people can do instead to be more sensitive.**

- **"What is his/her life expectancy?"**

"I can't think of a more insensitive question to ask someone," says author Marcy White. On top of asking about insensitive questions about a child's health, White says people often ask these questions while the child is actually present.

- **"Is he/she tired?"**

"I don't always feel the need to explain that when [my son] Jacob is not actively engaged in something, that's what he looks like." Often, people are too quick to judge a child by his or her appearance. Instead, stick to asking general questions about hobbies or the child's day.

- **"Let's get down to business..."**

White says, often in a medical setting like a doctor's office or a hospital, professionals tend to walk in and start the exams without any introductions. "Disabled children deserve the same respect one would give a verbal child," she emphasizes. Telling him or her about the procedure or how he or she feels today is one way to start.

- **Strangers staring**

White says there's nothing more annoying than having people watch her struggle in taking her son from his wheelchair into their van. However, she says, for the most part, people tend to step in. "It makes my day when someone comes and helps me. I wish I had fewer stares and more strangers' help."

- **People only looking at the wheelchair**

White says people often assume children with disabilities can't do certain things because they're strapped into wheelchairs. Instead of looking at just the wheelchair, White suggests asking what the child likes to do.

- **Safety rules that are different**

"When we go to the neighborhood outdoor rink I put my skates on and push Jacob around the ice in his wheelchair. Like most boys, the faster we go, the more fun he has. I wanted to take Jake to a local indoor skating rink one afternoon and was told that he could not go on the ice because it wasn't safe for him." White says parents are usually well aware of potential risks, and when people treat their child differently from other children, it only leads to disappointment — for the parent and the child. "We were offered free ice time to come back and skate alone. We declined because he wanted to do this activity with friends."

- **People who talk down to children**

If you're talking to a child in a wheelchair, go down to their level and don't tower over them, White says.

- **People who are scared**

White says some people are also too scared to start a conversation or don't know what to say to a child in a wheelchair. She says children often sense hesitation, especially if you don't come close to them.

- **"Do you like dogs?"**

White says it is common for people to ask her questions they want to ask her son. "People often ask me questions they would normally ask my child right beside me. I like to simply repeat the question for Jacob at his level, for example, 'Jacob, do you like dogs?'"

- **Dealing with people who think your child can't hear them**

Just because a child has a speech disability or any other kind of disability, White says this doesn't mean they can't hear or figure out what you are saying. There's nothing more hurtful for a parent than having to deal with intense questions or strange looks when their child is with them.

- **Just stop by and say hello**

White says the easiest thing you can do to make a parent's day is to say, 'hello.'