

## How to Support Parents of Kids With Special Needs

I have yet to meet a parent of a child with disabilities who hasn't heard a whole lot of nonsense from people who never intended to talk nonsense.

I'm not speaking of the jerks who say intentionally mean things. I'm talking about ordinary people – the well-meaning man at the grocery store, the group of friendly acquaintances at church, and even the best friends who, when face-to-face with the parent of a child with disabilities, say the wrong thing.

I know where they're coming from. I said some of these things before I became a parent of a child with disabilities, and I meant no harm. I believed I was helping.

Now that I know better, I want to share with you the long list of hurtful things parents of kids with mental, emotional, or social issues hear often. I'd also like to share a shorter list of things I wish I'd heard back when life was all crisis, all the time.

5 things you should never say to a parent of a child with special needs

What you said: "God never gives us more than we can handle."

What we heard: "You're fine. Quit whining."

The reality: We're not fine, and it's dangerous to bring up God with a person whose faith you don't know intimately (and sometimes even then). If you want to bring God into the conversation, please do so by listening, connecting, and being kind.

What you said: "He seems fine to me!" or "All kids do that!"

What we heard: "You're being dramatic or you're a huge liar."

The reality: Life isn't a courtroom. The person in front of you matters infinitely more than the facts. Acknowledge his or her pain. Even if I had been radically exaggerating the extent of Carter's crying (which most people never understood because he was distracted from his incessant wailing by new surroundings, new faces, and fluorescent lights), I was in pain and needed support.

What you said: "You must be a very special parent for God to give you such a special child."

What we heard: "We are fundamentally different and somehow deserve this."

This trope made me imagine God sitting at a school desk with a paper in front of him, listing babies on one side, parents on the other. God would draw a line from the most difficult baby to the strongest parent, then second most difficult to second strongest, and so on. Then a dog comes bounding in, distracts God, and oops! God sends the wrong baby to those wacky Joneses!

The reality: There was an accident with Carter's placenta or umbilical cord before he was born, and that accident broke Carter's brain. The damage is evident in his muscles, in his motor skills, in his ability to sleep, and in his social, emotional, behavioral, and cognitive development, among other things. I don't know why it happened, but I do know I'm not special. I just need you to see me and hear my struggle.

What you said: "You are an angel! I could never do what you're doing."

What we heard: "It's a good thing you can totally handle it and don't need anything from me!"

The truth: You could handle it. The alternative is...what? It's your kid. You handle it. Parents of special needs kids aren't different. Just like you, I kick ass at some parts of parenting, and I'm lousy at other parts. I'm very ordinary at most of it. You'd be horrified if you heard a group of parents of kids with issues like Carter's talking among ourselves. We use gallows humor and say very un-angelic things. Sometimes we are deeply angry.

But if you come to us and say, "I have a kid with problems, and I think I belong in your club," we will gather you into our circle and listen to you cry without asking you to stop. We won't encourage you to be strong because we know you are being exactly as strong as you can be. We know that your need is deep and that you can't handle this, even as you are in the midst of handling it.

What you said: "Every child is a blessing."

What we heard: "Suck it up, buttercup!"

The reality: Duh! Of course my child is a blessing. I love him more than I can believe. That does not invalidate my pain. In fact, my love is causing my pain because if I didn't love him, this wouldn't hurt so much.

What you asked: "Did you take medicine while you were pregnant?"

What we heard: "How did you cause this?" There are dozens of variations of this question, all of them seeking to lay blame at the feet of that traditional whipping post, dear old mom. When Carter was a baby, my friends who practiced natural and attachment parenting thought I wasn't doing natural and attachment parenting hard enough. My friends who practiced more conventional parenting thought I was spoiling Carter by nursing and carrying him so much. No matter which way I turned, someone needed to suggest it was my fault, as if I wasn't already trapped in a giant web of self-doubt and recrimination.

The reality: Ordinary, fallible parents do not cause serious disabilities in their children. We have not traumatized them into their problems by being human.

I now know that people look for causes because they want reassurance that this would never happen to them. And while I want to reassure you that it probably won't happen to you, it could. Yes, you – the one who gives money to charity and always wears your seatbelt and feeds your family organic foods and is a very nice person who never kicked a puppy.

I know that it can be very painful to live in a world of uncertainty and fear, but there are no guarantees in this life. We will never have answers to questions like, "Why this child? Why our family?"

It sucks, doesn't it? Yes, it does. And that is why we need you to refrain from the first platitude that comes to mind. Because what it tells us is that you want us to keep quiet – that you cannot bear to share even a part of our anguish.

If you truly can't, that's OK. If I had a way to escape the pain my family goes through daily, I would. But if you truly want to help (and I know so many of you do), I welcome you in. Here are a few tips.

## 8 ways to support a parent of a child with special needs

Listen. There is a person in front of you who is in pain. Don't leave her alone with it. Open yourself up to some scary emotions. Both of you will survive the journey.

Don't try to fix it. We have doctors and therapists and other professionals for treatment. And we've Googled every diet, book, supplement you might have to recommend.

Acknowledge and affirm. Say, "Wow, that sounds so hard." Say, "Oh my God, how painful!" Say, "I hate that it's so difficult for you."

Treat our kids the same way you treat other kids. Of course you should be sensitive – especially with kids who have emotional, social, and behavioral issues – because many of them don't want to be touched or may not be verbal. But in general, if you usually engage kids in conversation, do that with our kids too. Say hello. Smile. They might not respond predictably, if they respond at all, but they see you. And we see the effort you're making.

Offer to help, but only if you mean it. My mom sometimes came to my house and gathered every scrap of dirty laundry and brought it back clean and folded. Friends from church occasionally brought meals. Another friend drove Carter and me to his appointments when I didn't feel safe driving alone with him. Those things meant the world to me. And as much as I appreciated the clean clothes, meals, and rides, I was even more grateful to feel a little less alone.

Send a supportive note, text, or email. Parenting a child with special needs can be profoundly lonely. It's also hectic and chaotic and we may not respond to you, but do it anyway. The world starts to feel very far away when life is all appointments, crises, and chaos. Stay connected, even when it feels one-sided.

Work to understand a child's diagnosis. There is no need to become an expert, but an evening spent learning will only make you a better listener. If you don't know what to read, ask for suggestions.

Keep showing up and keep listening. There's nothing anyone in pain needs more.