

# What It's Like to Live with a Disability



As a polio survivor since I was an infant, living with a disability has been my “normal.” But, like most polio survivors, I just gritted through the limitations and inconveniences, trying to keep up with everyone else.

I’ve been thankful for the opportunities to speak to children about what it’s like to live with first a limp, and now the need for a scooter to get around, as several months ago I stopped being able to walk. My favorite thing to tell them is, “I am not my polio leg. I am *me*. You connect with me by looking in my eyes. When you see someone in a wheelchair, please look in their eyes, because that’s where the person *is*.”

In a world of increasing bullying and growing coldness toward other people, and in the hope of allowing compassion to grow, I’m hoping that you might find it helpful to know what it’s like to live with a disability. My disability is physical; I don’t really know what it’s like to live with an emotional disability, or an intellectual disability, or even a physical disability that is invisible but all-too-painfully real, such as deafness, cystic fibrosis, or debilitating pain. But some things are still true across the board.

In no particular order, here are some things I hope you find helpful in order to show more grace to folks like me.

**Everything takes longer.** The smallest personal care chores, like showering and getting dressed, or even fixing a cup of coffee, are harder and they consume time. (I'm still learning this, and apparently I'm a slow learner because I'm so optimistic by nature that I keep forgetting how long things really take.)

**Life is permeated with frustration.** On my first flight after losing the ability to walk, the American Airlines software wouldn't let the gate agent change my seat from the back of the plane. Strapped into an aisle seat that barely clears the arm rests of row after row of fellow passengers, being taken to my seat was hard. And embarrassing.

**Obstacles abound.** In a wheelchair or scooter, barriers like stairs and sand proclaim, "You can't go here."

**Social activities are restricted.** If a building isn't handicap-friendly (and having just two steps is enough to do that), there's no point even to trying to attend. Things are much better in the U.S with the Americans With Disabilities Act, but I won't ever be able to travel to Belarus again; the former Soviet states are so handicap-hostile that you almost never see a soul in a wheelchair. Many just don't leave their home.

**People stare.** Children are (quite understandably) curious about anything and anyone different, but still, the stares from both kids and adults silently shout, "You don't fit in. What's wrong with you? You're a freak."

**Am I invisible?** On the other end of the spectrum, it's amazing how few people will make eye contact with someone in a wheelchair or scooter. *Hey! I'm still here! Ready to interact with you!* Sometimes, waiters ignore patrons with a disability, not even asking for their order.

**Extreme weather is a nightmare.** Rain and snow are enemies of mobility equipment, especially anything with electronics. I

lost my first scooter to rain in Cozumel. [That was hard](#), losing my only means of mobility in a foreign country.

**Bathrooms.** Many bathrooms don't have stalls big enough for a wheelchair or scooter. In private homes, bathroom doorways aren't wide enough to get through. I'm sure you can imagine what a challenge that presents!

**It's expensive.** The tools and assistance we need are not cheap: walkers, canes, grab bars, widened doorways, raised toilets, and ramps—not to mention wheelchairs and scooters—are costly. You probably can't guess the price tag on an adapted car or van that allows a disabled person to drive.

**Losses.** We are continually facing the next "one more thing" we used to be able to do. And it hurts.

**Other people's self-centeredness.** I love to cruise; it's a perfect vacation for mobility-challenged people. But it is just staggering how many people will wait with me for an elevator and then rush inside to claim their place. It literally only takes a few seconds for an elevator to fill with too many people for there to be room for my scooter. Naturally, no one will look at me until the doors close.

May I make some suggestions for responding to those of us with disabilities?

**Please don't . . .**

**Please don't** try to fix us or shame us for being where we are. Some people have been asked, "What's the prognosis for \_\_\_\_\_?" When told it's progressive, some people have heard, "Well, it will be as long as that's your attitude!"

**Please don't** "help" us without asking. Some people have been grabbed by the arm to steer them or attempt to give support. I've had taxi drivers suggest that I shift my weight to my barely-functioning polio leg because it made sense to them.

Please, just let me figure out what I need to do to make things work.

**Please don't** assume it's God's will to heal everyone this side of heaven. If that were so, Paul would not have been given his thorn in the flesh and told God's grace was enough, and His power is perfected in weakness. (2 Corinthians 12)

**Please don't** assume our disability is because of unconfessed sin. Plenty of us have asked, "What did I do wrong?" and God, one way or another, has given us John 9 grace. "Neither this man nor his parents sinned," said Jesus, "but this happened so that the works of God might be displayed in him." (John 9:3)

**Please don't** try to explain what God is up to. Nobody knows the specifics of God's plan to bring good to us (and our families, and our friends) and glory to Himself. Let's just trust His goodness and give up on offering explanations.

**Please don't** try to make us feel better about our disability. Don't start any sentence with the words, "At least . . ." It's not comforting. It's minimizing.

**But please do** stay sensitive to God's leading on how to encourage us. One of my pastors asked me if I'd like to run a marathon with him in heaven, when we'll both have healthy, strong resurrection bodies. Now that was encouraging! Several friends have asked, "Would you allow me to bless you by bringing your family a meal?" (Then they affirmed me for not giving into my old pattern of "Oh, I've got this, thanks" independence.)

**Please do** let us know if you see Jesus shining through us. Many of us deeply, desperately want the difficulties and suffering of living with a disability to be sculpting in us "an eternal weight of glory, far beyond all comparison" (2 Corinthians 4:17).

**And please do** smile when you make eye contact with us.

Because we're not invisible.

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## Focus on What's Fixed

My husband and I recently took an Alaskan cruise. As we settled ourselves for sailaway in front of large windows on one of the highest decks, I heard a little girl ask, "Did we start moving yet? How will we know when we're moving?" I don't know what her mother said, but I do know the answer: you fix your gaze on what *isn't* moving.

I was looking at the building in this picture I took; when the ship starting pushing away from the pier, I knew we were moving because of our view through the window in relation to the stationary building.



And I thought, "Little one, the answer to your question is wisdom for life as well. Stay focused on what is unmovable, unchangeable, what is true for all times and all people in all places. Then you will be able to respond wisely to what moves and changes in your life and in the world."

This is true in both the small things and the world-shaking immense ones. Ray and I have been away from home for two and a half weeks, on an itinerary that has meant a lot of shifting and changing locations, unpacking suitcases one week and

trying to live out of them the next. We remind ourselves that the inconvenience is temporary because, Lord willing, we'll be home soon. That is a small, small thing made easier by remaining aware that "this too shall pass," that the comforting security of home and routine is right around the corner. But on the other end of the scale there are also horrible, horrible things happening in our world, particularly the explosion of Islamic terrorism in Iraq, persecuting Christians who are losing everything up to and including their earthly lives. West Africa is seriously shaken by an Ebola outbreak that is causing instability in everything. If that's not enough examples for you, Lael Arrington recently blogged here about "[Five Ways to Dispel Dread](#)."

It can feel like the world is wobbling on its axis. Even our own little worlds. It is crucial to keep our eyes on the One who says, "I the Lord do not change" (Malachi 3:6), on the One who promises, "I will never leave you or forsake you" (Joshua 1:5). We need to stay focused on the unchanging Word of God, in which He reveals that He knows how the future will unfold, and has everything under control-even the end-times horrors that appear to be right around the corner.

Later on our cruise, as we were sailing from one port to another, I knew we were moving-apart from feeling it-because I could see the churned-up wake next to the ship. But in order to tell how much we were rolling from side to side, I focused on the horizon which appeared to rise and fall. But since I knew it was unmovable, that meant the rising and falling was happening on the ship. I sat looking out the window, gazing at the horizon that reminded me of God's unchangeableness. A good and loving God is always, always in control. I am so glad.

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