

# 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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## Remodeling a Home—and a Soul



We are in the midst of a major remodeling project in our home as it is made wheelchair-friendly. Doors are being widened, our closet is being reconfigured so I can reach my hanging clothes, and our bathroom's tub and step-in shower are being replaced by a roll-in shower.

I have been struck by the similarities between remodeling a home and remodeling a soul—otherwise known as the sanctification process. Sanctification means “being made holy,” and holy means set apart. I am being set apart for God's kingdom, for His purposes, and with a plan to make me into the image of His own dear Son (Romans 8:29).

The first thing that happened was that things got moved. Our

bed was moved to an enclosed porch, which is a great blessing given the amount of construction dust in our bedroom. Our hanging clothes got moved to rented racks in our dining room, along with all the suitcases and other kinds of things on shelves. (It pretty much looks like a bomb went off in our home!)

When God is remodeling our soul, He also moves things, particularly moving us out of our comfort zone. We get moved into a *discomfort* zone—a change zone, a growth zone. In this part of the process, we can find out how easy it is to make idols of comfort and the status quo. And like all other challenges and trials, the answer to the test is to trust God and rely on Him.

Before making any changes, the project director went up in the attic to check the load-bearing walls. I was so glad to learn this; it meant that nothing would be torn down and taken out that would weaken our home and make it unstable.

When God is doing the remodeling, He takes into account how we were designed and built (by Himself!). He knows how much stress we can take, and won't violate His own design for us. Just as He promises us not to allow us to be tempted beyond what we are able (1 Cor 10:13), He always remembers that we are but dust (Psalm 103:14), and He knows our limits.

The trim around doors was pulled out, and sections of sheet rock were cut out and removed. The garden tub was cut up and hauled away, and the huge mirror over it is now gone. The glass shower was taken out.

I've noticed that part of the sanctification process means God removes the old things in our hearts that have outlived their usefulness—things like coping strategies and childish ways of thinking and living. In order to grow us up to maturity, the old has to go.

They parked a trailer outside our back door, and it was soon

filled with sheet rock, wood, marble and glass that needed to be taken to the city dump because it was trash. I mentioned this to the man in charge, who cheerfully agreed that "You gotta get rid of the ugly!" Since I also shared with him my thoughts about the parallel to sanctification, he laughed with me that that's what God does: He gets rid of our ugly. He targets anything that's not glorifying to Himself or helpful to us, and pulls it out. Or calls us to let it go into His hands.

I noticed there is a definite order to things. The open spaces for closets and bathrooms were widened before installing new doors. The walls were textured before being painted. The bathtub was pulled out, and its faucet and spigot were removed, before the tiler comes to give us a beautiful new wall.

This made me realize that God knows the best order for addressing issues in our lives that need to be changed. Like knowing which are the load-bearing walls, He knows what needs to wait until He deals with other problems first. For example, we often want Him to get rid of nasty habits or addictions, but He's more interested in working on our hearts so that the change in our behaviors is a more (super)natural, organic result of growth.

Remodeling a house means a lot of inconvenience. I have to go to a gym that has a roll-in shower because our other shower is in a bathtub, and I can't climb in and out of bathtubs anymore. We are having trouble finding some things that were moved temporarily. There is dust everywhere. I can't have people over very easily. These are all temporary, but they are still inconvenient.

God's remodeling process also feels inconvenient because there are so many adjustments to new ways of thinking and reacting and living. We have to practice new ways of thinking when God makes changes in our belief system and our trust system.

Adjustment means change, and change is rarely convenient!

The owner of a construction company that does these remodeling jobs for mobility-challenged people like me has a picture in his mind of what all these changes will look like in the end. I have a vague idea of what changing the entrance to our bedroom will look like, and how the reconfigured closet will work, and what it will be like to roll into the shower, but he has a very specific plan in mind based on experience and knowledge and wisdom.

My heavenly Father has a very specific plan for my remodeling too. He knows what making me over into the image of His Son means, so I will look like Sue and Jesus both.

And just as I need to trust the architect of our home remodel, even more I need to trust my Father, who knows what He's doing in remodeling my soul and does it all well . . . and in love.

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## **“This Too Shall Pass”**

*I wrote this blog post on May 7, 2012, not quite five years ago. I had no idea that by this point, I would hardly be walking, using a scooter 95% of the time and unable to move without a walker for the rest. Pain and serious weakness are my daily companions. As I noticed the counts on my most popular blog posts and discovered this one among the top, I am grateful that the wisdom God gave me five years ago is even more true today. And I am grateful that I can even minister to myself . .*



Sometimes it's the simplest things that help us navigate life. The old, old adage "this too shall pass" is one of them.

No matter what trial, grief, trouble or challenge we face, there is comfort in reminding ourselves that it's temporary. Some are very short-lived—the time crunch of a deadline, the pain of recovering from surgery, waiting for results of a test or an application. We can remind ourselves, "By this time next week (or month), this will be behind me. This too shall pass."

Some are very long-term—a permanent disability like [my polio](#) or my dear friend [Lael Arrington's](#) painful rheumatoid arthritis. The death of a loved one, or a marriage, or a cherished dream. The realization that God is choosing to give us grace for, not deliverance from, our thorn in the flesh. Even so, when we remember that our time on this earth is short compared to our life on the new earth, we can remind ourselves, "A hundred years from today, this trial will be just a memory. I can either be glad for how I handled it, or regret the short-sighted choices I made. Because this too shall pass."

It's helpful to remember that even the good times, the fun times, the stress-free (or low-stress) times will also pass, because life is like that. When we remember everything is temporary, it helps us hold onto sweet moments and days with a looser grasp while reminding ourselves to be grateful for the blessings we're enjoying because "this too shall pass." If we are mindful of the transience of the good days, we won't be devastated when they dissipate.

"This too shall pass" is one way we can live in light of eternity, keeping our earthly life in perspective. When the hard times come, whether moments or years, we can comfort ourselves with the truth that "our momentary, light suffering is producing for us an eternal weight of glory far beyond all comparison because we are not looking at what can be seen but at what cannot be seen. For what can be seen is temporary, but

what cannot be seen is eternal" (2 Cor. 4:17-18).

When the good times come, we can give thanks for the way they point like signposts to heaven's unending joy.

Which will NEVER pass away!

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