A Christian Leader Whose Husband Has ALS Sounds Off on the Ice Bucket Challenge

Well, we are on week two of the very-viral very-everywhere ALS ice bucket challenge. I know, I know, I can hear the groans; it started out cute and now it's out-of-control. Played. Clogging up social-media sites everywhere.

I even read this charming article in which the author called the challenge (that has raised an unprecedented amount of money for one of the most outrageously underfunded diseases) a waste of fresh water. Another headline whined, "Is the Ice Bucket Challenge Going to Cure ALS?" Um, no (and, by the way, that's a stupid bar to set for any fund raiser.)

Critics complain that the challenge is really about feeding our American narcissism and does nothing for ALS awareness or funding. They assert that people should just quietly donate their money and move on with their lives.

I get that they're cranky, but I think maybe they don't realize what it's like to face this insidious disease and then realize that it's nearly invisible to the rest of the world. As I watch my husband become entombed inside his own body, I feel desperate for people to understand that this sort of inhumane condition exists. But for some reason, while everyone acknowledges it's one of the worst fates imaginable, funding for research and patient care is nearly nil.

I recently mentioned to a doctor that my husband has ALS, and she first looked confused and then said, "Oh, that's Lou Gehrig's Disease, right?" *Right.* Why does she—a doctor of medicine—still only know it by Lou Gehrig's Disease? Because we humans need to associate things with people. It's easier that way. That's why the celebrity faces and personal

challenges happening in the ice-bucket challenge are so effective at bringing in money. And if someone gets to look good while plunking their $50 into the ALS tip jar, *I have zero problem with that*.

Because here's the deal: We are in for the fight of our lives with this monster, and the very LAST thing I want is for people to give quietly, anonymously, and then slink away. Raise the roof! Raise a ruckus! Call all sorts of attention to yourself! I will be happy for you and every Facebook Like you receive, as you nudge ALS an inch or two closer to the collective public consciousness.

So, fear not, dear reader, this too shall pass, and your Facebook news feed will go back to cat videos and kids singing "Let It Go." Until that happens, here's a little reminder about what it's like to live with ALS and why this level of awareness is like gold to families such as mine.

A Mile in ALS Shoes

People ask me often what it's like to live with ALS. It's a brave question because the answers are not very pleasant. But it's also such a worthy question because understanding how this disease impacts those who suffer from it creates empathy, which is so valuable; it carries us into another person's world and allows us to understand what they're feeling and how they're hurting. As I watch my strong husband struggle with things that used to be easy and automatic, I sometimes wish that everyone could see life from his perspective.

If you would like to experience just a tiny corner of an ALS life, I have a list of Empathetic Experiences for you. These are things you can do to walk for just a mile in ALS shoes. If you try one, take a little time at the end to consider that people actually living with the disease have a million miles more to go.

1. Pick up a 10-pound weight. Now imagine it’s your fork and move it from your plate to your mouth repeatedly without shaking.
2. Sit in a chair for just 15 minutes moving nothing but your eyes. Nothing. No speaking, no scratching your nose, no shifting your weight, no changing the channel on the television, no computer work. Only your eyes. As you sit, imagine: This is your life. Your only life.
3. Borrow a wheelchair or power scooter and try to maneuver quickly through the aisles at Walmart, without speaking. Note the way people react to you.
4. Strap 25 pounds to your forearm. Now, adjust your car’s rear-view mirror.
5. Using none of your own muscles, have your spouse or child or friend get you dressed and brush your teeth. Write down some of the feelings you have being cared for in this way.
6. Before you eat your next meal, take a good, long look at the food. Inhale deeply and appreciate the aroma. Now, imagine never being able to taste that—or any other food—for the rest of your life.
7. Put two large marshmallows in your mouth and have a conversation with your friends. How many times must you repeat yourself? How does this make you feel?
8. Go to bed and stay in one position for as long as you possibly can, moving nothing.
9. Strap weights to your ankles and climb a flight of stairs, taking two at a time. That’s the kind of strength it takes for someone with ALS to tackle the stairs on a good day.
10. Install a text-to-speech app on your phone or iPad and use it exclusively to communicate for one day.

And to my friends living with ALS: Please give us more ideas

and help us move into your world for a bit. We want to help make your lives rich and full, and I’m not sure we can do that without at least a basic understanding of what you are facing. I think I speak for many when I say: You are superheroes, and we are in awe.

With unending hope for a million-mile cure.

Bo Stern *is a blogger and author of* Beautiful Battliefields *(NavPress). She knows the most beautiful things can come out of the hardest times. Her Goliath came in the form of her husband’s terminal illness, a battle they are still fighting with the help of their four children, a veritable army of friends and our extraordinary God. Bo is a teaching pastor at Westside Church in Bend, Oregon.*