

Are You Afraid to Ask for Help?

Somewhere in the hazy fog of the past crazy week, I came to a realization and it is this: I have become exactly what I planned *never* to become. Well, let me rephrase that: I have become what I *hoped* I would never become. Had I actually created a plan to not become it, I would not be in this pickle now (wherein pickle is defined as: teetering on the ragged edge of burnout and meltdown.)

In the beginning of this ALS battle, countless people warned me: *you have to take care of yourself, too*. And I nodded in agreement – and I mean *real* agreement, not that condescending, falsely humble, “Sure, friend, thanks for sharing that piece of advice that I will never actually use,” agreement. Not, “Yeah, I already know this stuff and have it dialed,” agreement. I knew going in how important self care would be.

And the thing is: I do actually like myself. I’m neither martyr nor masochist. I do have some INTJ-related workaholic tendencies, but I can down-time like a champ when I know I need to.

So this is the week I’ve been forced to ask the question: how did I get here? How did I end up in this ditch of discouragement and numbness and frustration? The answer is clear and you’ve probably already guessed it, but the reason behind it is sort of funky. I am in this emptied-out place because I have not asked for enough help.

Bottom line, Steve’s care has grown beyond my ability to handle by myself. I have been away from him six nights in 2014 – all for ministry trips – and in the course of those six days away from home, I have spoken twelve times. The trips have been excellent, but they haven’t been relaxing.

In July, our lives changed dramatically as ALS took center stage and began to eat away at our nights, stealing the precious, replenishing resource: sleep. (Seriously, if you have access to endless nights of uninterrupted sleep, take a minute and thank the Lord for this great gift. We take it for granted so much, but it is an essential foundation piece for every other thing.) (Did I sound like your mom just then? Sorry.)

As the opportunity for sound sleep ebbed away, so did my ability to think clearly, process cohesively and maintain even trace amounts of the me I used to be. Not that the me I used to be is so special, but there is something about pre-ALS Bo that I miss and longed to reconnect with.

The other thing that crept in not-so-subtly was a reluctant resentment toward these responsibilities and ALS and life in general. I'm not proud of this, but it is what it is. Instead of examining the resentment and dealing with it, I would just beat on it with the Guilt stick. I addressed my need for a break to breathe by reminding myself (see mom voice above), "STEVE doesn't get a break from ALS. You're fine. You'll be fine. You're not losing your mind." Except I sort of was.

The main reason caregivers burn out is a reluctance or inability to get the help they need. The reasons for that reason vary wildly. Some cannot trust others with their loved one's care. Some feel guilty, like they're handing off their problems to other people. Some don't think their spouse would be open to anyone else caring for them. And some, quite simply, don't know who they could ask. While these are all at play in my situation, they are not my primary issues.

My issue is this: I am lazy with myself. And I have reached levels of exhaustion where the idea of making another phone call or teaching someone how to take care of Steve feels like way more work than just doing it myself. I have made some

half-hearted attempts to find help at night, but as soon as it doesn't work out I give up and crawl back into my hole of despair. And honestly, I think this is the issue for many ALS spouses (and all others who care for the terminally or chronically ill): they don't *want* to go it alone, but they are too deep in to be able to work their way out. Their community of friends and family watch helplessly, not knowing how to intervene while the caregiver insists she's got it covered. She doesn't. She just doesn't have the first idea about how to plug people into the holes that she has been filling for so long.

So, back to my story: Long night after long night culminated in a meltdown at the breakfast table one morning with my daughter, Tori. I have been reluctant to share how I'm doing with my kids for fear they would be overwhelmed by it and feel like they have no fully functioning parent in their lives. On the contrary, that beautiful girl spoke strength and wisdom into my heart like none other. She preached at me. She comforted me. And after that, Whit called me to let me know that my sisters and brothers-in-law were coming for the weekend so I could get some sleep and do something fun the house.

I'm not ashamed to say: I cried like a silly when I got that news. And that's when I made a crazy decision and sent Whit a text: "Would it be bad if I went away? Like away away?" I knew it would be tough to step back and let this (very capable) crew step in if I was on the premises.

I knew I would not be able to show someone else how to empty the suction machine if I was there and could just do it real quick. I also knew that if my sisters (who are my very dearest friends) were in my house, I would spend all my time talking to them and zero time on the processing I knew I really needed. For several weeks my dearest dream had been to get a hotel room and sleep and think and cry and be. But I was

worried.

I worried about how Steve would feel when I told him I was leaving just to leave. I worried it would look like I was running and, candidly, I care more about what the watching world thinks than I should. I'd love you to think I'm awesome and strong and I would have kept this whole little thing a secret, except for one thing: the other caregiving spouses out there who are breaking beneath the weight of their load. Many of them read this blog and I cannot afford to show them a painted-on, propped-up version of myself. If I pretend that I don't need help, they will feel guilty and weak when they do. *And they do.* We all do.

So, that's the backdrop for what would become one of the most wonderful 18 hours ever. Since I'm already over 1,000 words, I'll save the trip recap for tomorrow, but check back in because it's very cool. And also? I'm writing this post at the breakfast table from my favorite lodge in this whole world and I just wanted to flaunt that information for a second. In two minutes, I will pay my bill, get in my car and drive back to my life and the man I love more than any human on this planet. And I cannot wait to see that wonderful guy.

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