

5 LESSONS I HAVE LEARNED FROM BEING A YOUNG CAREGIVER FOR MY HUSBAND WITH ALS

By Sherlyn Brubeck



In January 2014, my husband Ryan was diagnosed with ALS at the age of 37. Shortly before his diagnosis, we were at a high point in life, celebrating our one-year wedding anniversary and expecting our first baby.

In only a few years, I have become the primary caregiver to my husband and our young son. This challenging, but important role has taught me numerous lessons about life, love, acceptance and giving to others.

1

LIVE LIFE IN THE MOMENT

I never knew what that truly meant. I thought I did, and I thought I appreciated and enjoyed each moment – until Ryan was diagnosed with ALS. As his disease has progressed and his physical abilities are now rather limited, I have come to realize there are many dreams I had for us as a couple and as a family that won't be fulfilled. I have had to start accepting that Ryan and I are not going to be able to do the things that I always dreamt of us doing together. That, good or bad, our life is ending up very different than what I envisioned, and therefore it's critical to treasure the moments and be present for each experience that we do have together.

2

IT'S OK TO ACCEPT HELP

This is so cliché, I know. As a full-time working mom with a husband suffering from ALS, there are many moving parts to our life. I have learned that when someone offers to bring dinner, to take our son for an overnight or any other of the hundreds of kind gestures we have been blessed with, it is OK to accept. People genuinely want to lend a hand. Our home is a revolving door and privacy is hard to come by, but without our village we would not be able to do get through the daily struggles.

A huge part of our village is the team at the Les Turner ALS Foundation of Chicago. The staff of the Les Turner ALS Foundation has held our hands every step of the way through this wild journey. When we were first introduced to the Les Turner ALS Foundation we had no clue as to how important they would be to our lives and I was not prepared to be a caregiver. Their team can be counted on to root us on, cry with us, advise us and even celebrate the birth of our son.

3

NO ONE GETS IT UNTIL THEY HAVE WALKED IN YOUR SHOES.

And I don't even mean the same size, the same brand, or even the same style (you get where I am going here). Unless someone has experienced your exact journey, they will never fully understand your challenges or your triumphs, and that's OK. As a caregiver, I find that I want – and need – to seek out others in my shoes. In many ways, speaking to other caregivers exposes me to people who can relate to what I am going through; however, in other ways, it can be a challenge. The average age for a person diagnosed with ALS is 55, not 37. Though speaking to other caregivers of people with ALS is helpful, I find myself envious, at times, of the extra time they've had with their loved one. I'm still learning how to absorb other caregivers' advice and stories, and appreciate and apply their lessons to my own life.



4

YOU WILL NEVER BE FULLY PREPARED.

Always Be Prepared, "ABP", is my motto and has become a joke between Ryan and me. As the ultimate planner, when Ryan was diagnosed with ALS, I went into planning overdrive. I thought that if I could plan and coordinate everything, then maybe in some way it would make this journey more bearable. Oh how wrong I was! ALS is not a disease that you can plan for, and you certainly cannot plan on your emotions cooperating.

Just when I think I have a handle on my role as new mom and caregiver to my husband, life whacks me over the head, and my emotions often fail to get the "ABP" memo. I find myself trying my hardest to do "normal" things, like take my son to a Halloween party or attend a friend's wedding. And just when I think, "yes, you are doing this," tears start to well up in my eyes. At said Halloween party I looked around the room at the moms and dads doting on their toddlers and I was overcome with sadness. This is all I ever wanted for Ryan and I, and he would have loved to have taken part with our little costumed baby. Or, I find myself at a wedding and the dancing starts. I love to dance, and I love to dance with my husband. I sit there holding back tears.



5

YOUR PERSPECTIVE IS FOREVER CHANGED.

This is a tough one. I find myself out with friends and they are venting about typical challenges: a husband who travels too much for work (but at least he's not sick), a husband who doesn't take her out enough (but at least he's not sick), a husband who doesn't help out around the house (but at least he's not sick). And then there is the opposite experience. Some friends are afraid to share their hardships because they seems trivial compared to what we are experiencing. Numerous people have told me that we are their perspective. When things are bad, they think about our situation. Of course, they only mean this in an empathetic way, but it is very sobering to accept.

The irony of our situation is not lost on me. When I went into the hospital to give birth to our son, Ryan and I both required wheelchairs. As I prepared to give birth, I was more concerned with the nurses caring for my husband and making sure he was comfortable. As our son was beginning to walk, my husband was losing his ability to walk; and as our son begins to speak, my husband's speech is becoming slurred. As I cope with the emotions of watching my husband's body deteriorate, I get some relief from the happiness, youthfulness and curiosity that our son brings to our family.

I share all of this with you to demonstrate that we are only human. At the end of the day we are all just trying to figure it out. The one person that has more wisdom, humility, graciousness and perspective than anyone I know is Ryan. He gives me my strength. Without him, without his whispers of I love you, his winks, his soft reassuring smile, nudging me forward with every step, I would not be who I am. Ryan, you are my everything. You are my strength, my heart, my peace and I love you with all my heart.

Sherlyn Brubeck is a Certified Financial Planner™ just outside of Chicago. In her free time she enjoys spending time with her husband, Ryan, and their 18 month old son, Ryan, Jr. Sherlyn has made it her personal mission to increase awareness and advocacy for the ALS community.