

When the “Happiest Time of the Year” Feels Like Anything But

On a foggy, frigid day in the winter of 2011, a doctor in a white lab coat told us that my husband was dying. She spoke with great care and compassion and then gave Steve and I plenty of room to bleed as our lives were torn open like so many who had sat in that office before us. In our 26 years together, my husband had never known a single significant health issue. I sat in stunned silence, mentally recounting the list of things I knew about the monster that is Amyotrophic Lateral Sclerosis (ALS). Always fatal. Two to five years. Slow, steady paralysis that ends all ability to speak, swallow, move and eventually breathe. As the facts scrolled through my mind like a movie marquee, I struggled to catch my own breath, to process the prognosis, to stay upright. And I knew that life would never be the same.

Our determination from the very beginning was to find the beauty in every minute we were given. We set our hearts to search out the love of God in the middle of our mess. We reminded our family to focus on the character of God. We prayed for healing. We prayed for His purpose to come alive in us and for His kingdom to be extended amid our suffering.

Sometimes it worked really well and we felt supernaturally sustained in the middle of our grief. Sometimes it felt like we were swimming through quicksand, but somehow we found our way to the warm winds of summer. We spent some time traveling with our kids, pretending we had all the minutes and money in the world. We let them choose dream trips with Steve and used every last, happy dime of a timely tax return making those dreams come true. It was still painful, but the distractions and new discoveries made it bearable.

As the dog days of summer surrendered to the crisp mornings of fall, anxiety moved in as well. I knew change was coming, and I didn't feel ready but could think of no way to stop it. Autumn arrived, slow and steady, like the tide takes over the shore, washing away the last remnants of our dream-making summer and bringing a whole new pressure with it: the holidays.

Forcing, Then Finding, Christmas

I love Thanksgiving and Christmas—I really do. But now as I shouldered the bulky weight of grief, these relentlessly happy days seemed impossible.

I probably would've boycotted the festivities altogether, except I had children who desperately needed something—*anything*—to feel normal, and a husband who was counting his remaining Christmases very carefully. We couldn't afford to let one slip by us. So I decided I would pull myself up by the bootstraps and sink all my mental muscle into making it the hap-happiest season of all.

That decision didn't last very long. I made an elaborate Advent calendar (the first ever in my family's history) filled with fun things to do together each day. I lugged bulging boxes of decorations from the garage but couldn't bring myself to open them, knowing they were filled with endless memories of Christmases past. Better Christmases. I took the kids to get a Christmas tree, something Steve had always done, and we set it up and dressed it with the same old decorations, listening to the same old carols and drinking the same Swiss Miss hot chocolate, hoping maybe we could outwit our sorrow if we used the snowman mugs.

At the end of the evening, I sat in my quiet living room, looking at our beautiful tree as tears dripped onto the pages of my open Bible. It was the same tree but a different me. For the first time, I felt disqualified from Christmas. It was as

if I were standing on the outside of a sparkling house, looking through a foggy window at all the happy people inside. I wanted to go in, but my shoes were caked with the soil of the battlefield we were walking every day. I no longer belonged in that pristine picture.

Desperate for hope, I turned to the only refuge I've found never fails: the Word of God. I decided that instead of abdicating the holiday season to ALS, I would lean into the Christmas story. I read it every day, in every gospel, in every version I could get my hands on. I read Isaiah's prophecies about the Messiah. I studied all the characters and their backstories, imagining the questions I would have asked Joseph or Anna or one of those swing-shift shepherds if I had the chance. In this new world with no maps, the Christmas story became the compass I clung to, using it to steer myself toward hope. Because, it turns out, Jesus came for the sad people too.

Isaiah says it best when he tells us that a beautiful baby King would come to those "sitting in darkness" (Is. 9:2). Matthew repeats Isaiah's words (Matt. 4:16), reminding us that Jesus didn't come because the world needed a little more light, He came as its *only* light, its *only* hope. As I read this verse over and over and over, I felt this truth begin to seep into my spirit like water seeps into sand; my heart, broken and bleeding, belonged in the story. When I couldn't find my way to Christmas, it found me. Jesus found me.

Tips for Finding Hope

Now, three years into Steve's diagnosis, I can say that we have experienced some of our most meaningful, magical holidays right here on this battlefield. It's a miracle to me, but I am absolutely convinced that the comfort of Jesus can reach into the most difficult days and create something worth celebrating. I've talked with so many hurting people and heard so many heartbreaking stories. I never want to trivialize the

pain they are going through in this fallen, frustrating world, but I do want to nudge them toward the hidden hope that can be found in the hardest places.

Finding that hope is not an exact science, but here's what's worked for me:

- **Embrace the dance of sorrow and joy.** We're so conditioned to feel either sorrow or joy that the presence of sadness on a happy holiday can seem jarring. It's tempting to back away from the blending of such powerful emotions by either checking out of the holiday or by stuffing our sorrow away where no one can see it. In fact, I fear we've put such a premium on joy in the church today that we've lost our ability to lament in healthy ways and have learned instead to put on a happy face and hope no one knows we're dying inside.

Sorrow is not sinful. In fact, sorrow is a gift to us because it invites the comfort of Jesus near. And in His presence there is fullness of ... joy (Matt. 5:4; Ps. 16:11). It really is a lovely dance when we give ourselves permission to acknowledge the emotions that go with all our wins and wounds.

- **Get a good flashlight.** John 1 is my favorite version of the Christmas story. It goes like this: "*And the Word became flesh and dwelt among us*" (v. 14). Jesus, the living Word, took on our pain and sorrow and moved right into the heartache we call home. His word, *the Word*, comes as a light into our darkness, to illuminate, to direct, to protect and to comfort.

I have several go-to verses stored in my memory bank for that moment when the darkness falls. You know the moment. Maybe it's driving to a party you wish you didn't have to attend. Maybe you're facing a pile of bills or shopping for gifts you can't afford or remembering when life felt easier. Those are the moments when darkness can crash in like a sneaker wave,

and that's when I turn to my arsenal of truth. I speak those verses over my life and into my darkness over and over again until I feel safe and steady. (A few of my favorite flashlight verses: Deuteronomy 20:1, Psalm 5:11, Jeremiah 17:7-8 and James 1:2-4.)

- **Refuse to resent.** The thing is, happy people still exist. Some of them are faking it, but many of them are legitimately living in an abundant season of life, and they want to enjoy the holidays. Sometimes they'll understand what you're going through and sometimes they won't. Sometimes they'll say really insensitive things, and sometimes they'll be flawlessly encouraging. Determine to bless them and their happy selves no matter what.

Resentment is a trick that leads to bitterness, and bitterness is a ditch. People will help you justify your right to be in that ditch, but no one really wants to move in there with you. One of the best ways to stay free of bitterness is to stop resentment before it has a chance to start by being willing to smile with those who rejoice.

- **Find someone who needs you.** Because someone does. Someone, somewhere needs your hope, your heart and your God. Throughout the course of our fight with ALS, we've run into countless people who just needed someone to listen to their story, to hear about their heartache without judgment—maybe even without offering answers apart from “I love you” and “I'm praying.”

There's something about moving out beyond the shoreline of our own suffering that helps us see life from a new perspective. During this season in our lives, we adopted a child to sponsor through a humanitarian organization. My husband meets regularly with men who are struggling in their marriages. Our kids are active in raising awareness and funding for ALS research. We find meaningful but doable ways to meet even

small needs in the world outside our war, and it helps to remind us that we are not defined by this struggle. God is still using us to bless others, as we ourselves are being blessed.

- **Recognize and respect your own limits.** The holidays are busy enough without adding the weight of crisis or heartache to the mix. Initially, I wanted to do everything the way I had always done it, hoping to prove to my family and myself that life could go on as normal. But I was wrong. Life could not go on as normal because I wasn't working with the same emotional reserves I had in years past. I had to be willing to make some changes, and those changes involved adjusting my expectations about what a perfect Christmas would look like and humbly accepting help from those who offered.

Friends stepped in to lend a hand with cooking, shopping, wrapping and all the things I used to be able to do on my own. And I gradually let go of the notion that we could create a holiday so beautiful that my family somehow would forget we were fighting a fierce battle. In fact, we stopped trying to keep our pain buried beneath the tinsel and holly and instead let it push us toward the comfort of Jesus.

Somewhere in that swirling, stormy season, I realized that we did not have to recreate the Christmases of years past. We could let the Holy Spirit breathe into our grief and create something new, deep and uniquely lovely. I believe that as I learned to respect the fact that I was powerless to fix our situation, it opened the door for our Great Emmanuel to come to us, and He was perfect in our weakness. There, on our individual patches of broken ground, He met with us and reminded us why He had come in the first place.

In acknowledging what we cannot do, we make way for the amazing things that only He can do. For those sitting in darkness, the light dawns. To our shadows, suffering and

overloaded shopping lists, Jesus comes. And He brings salvation with Him.

Wherever you find yourself today, know that He is with you. Lean into the truth of the Christmas story: The God of the universe wrapped Himself in swaddling clothes and came for a broken world and a broken you. Keeping your eyes fixed on His story will change the way you see yours, and that will change the way you see this holiday season and all the seasons to come.

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Bo Stern shares her family's story of fighting against Lou Gehrig's Disease at