

Excerpts from *The Widow Chose Red?* By Rachel Kerr Schneider

John and I had been married for 21 years when everything changed. We had a marriage built on trust, respect, and faith. We enjoyed a relationship based on support and substance. We were blessed, we were a team who could tackle any challenge and function fabulously under pressure. We dealt with a lot, especially during his last three years. When our life became an insurmountable challenge, I wondered if my faith was enough. I feared I wouldn't be able to handle the curveballs thrown at us. I had so many questions. How was I to keep living while someone I loved was dying? How could I make the dying process a "normal" part of living? I knew we had to give God total control of our lives and the situation, knowing those things didn't define us, and He would use them to refine us if we would surrender them to Him. But how were we to continue living with a diagnosis of death?

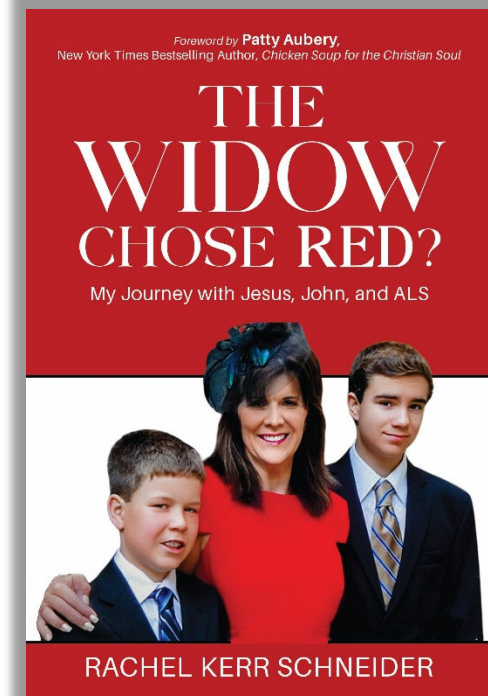
And there I was. At the age of 22, I had my first bona fide interaction with a certified real gay person. And guess what? Lightning didn't strike either one of us. Ronald didn't morph into a different person, and my feelings for or toward him didn't change. He was still the smart, witty, successful, fun, explosive, volatile guy that he always was. He knew how "religious" I was, so it was probably harder for him to share than I realized.

It isn't that far-fetched, is it? John and I met in July 1985 and by September 1987, we were husband and wife, driving to our new home in my just-had-to-be-repaired-to-the-tune-of-one-thousand-dollars white T-top Cutlass Supreme. What a perfect way to begin our life together, a mega-hour-day road trip in a questionable car.

I eventually landed a position as an account executive with a real estate-based advertising agency in downtown Philly. They thought I was a great representation of Delta Burke from *Designing Women*. Big hair, southern drawl, and mounds of makeup. You get the picture.

I learned that in big urban areas, pigeons are everywhere. And before I knew it, a pigeon pooped on top of my head. I've heard it is good luck. REALLY? I was mortified. I had big hairspray hair. I couldn't just rinse it out! So, I stepped into McDonalds, found the bathroom, and worked on getting the white poop out of my hairspray hair while trying not to mess up my entire head. Emily was cracking up. I thought she was going to wet her pants. Me? Not so much. I wish I could say that things got better after the pigeon poop incident, but they didn't. It seemed that adjusting was becoming my way of life, requiring more resilience with each passing day, and I was struggling to keep getting back up.

At the end of the service, as the pastor was greeting everyone leaving the sanctuary, John and I hung back. We knew we would need more time than a normal, "A good sermon, thank you for your words, or good to see you." I was so excited I could hardly contain myself. By the time we got to Pastor Greg, he looked at us and said, "I think I know you guys." I said, "Of course you do. We're Rachel and John Schneider. We knew you back in King of Prussia, Pennsylvania." He looked at John and said, "You're with the truck company, right?" John answered, "Yes, I am." Pastor Greg said, "Well, I was looking at you guys and then I got this awful feeling. Oh no, I don't mean awful. I mean I got this feeling that maybe I knew you. What are you doing here?" I answered, "Well, John got promoted and now we're living here,



and we're expecting a baby." Having the connection with Pastor Greg was nothing less than Divine Intervention. My time in Chicago was one of the more difficult phases of my life. Part of it might have been postpartum, but it was a difficult time in our marriage.

I found a counselor and I strongly suggested to John that we go together, at least for a couple of sessions. He didn't believe in counseling, but he went because he saw how much it meant to me. I kept going long after he stopped. I realized through counseling that John was not completely responsible for my happiness, and I wasn't completely responsible for his. We made adjustments and our church life was a huge piece of that.

Then, years later, through a conversation, she answered my unspoken question. She shared how they had a lovely dinner that evening and then everybody went to bed. It was an evening not very different from all the others. Elaine said that around four o'clock the next morning, she woke and felt a different presence in the house; an angelic presence. She didn't see anything, yet she sensed a different energy and didn't know why. When Ronald didn't come for coffee, she checked in on him and found he was gone. She was peaceful, of course, yet so very sad. There wasn't panic or her running through the house, wailing. She had been prepared by what she felt earlier that morning, even though she didn't know what it was about.

If there's anything I can encourage us to take from this part of the story it is that we need to trust ourselves; to trust in this gift we've been given and recognize that we are a spiritual being living in a human body. The Holy Spirit indwells us and speaks to us, and we need to know, receive, and believe that. It's like Elaine had a peace that passed her ability to understand it, as declared in Philippians 4:7.

The year was 2008 and John's symptoms showed themselves almost in a stealth-like manner. He had always been an athlete and was inclined to brush off minor strains and unusual aches. He thought it was a simple pull of the hamstring. Perhaps one foot on the dock, the other in the boat had caused an unexpected pull and other annoying symptoms. However, over a period of time, these symptoms were not going away, and they were not getting any better.

The boys were asleep, and I was tucked in and reading a book when John came home. He looked frightened and was as white as a ghost. He came over to my side of the bed, sat down and said, "They think I have this disease, ALS. And I'm going to die." He couldn't catch his breath. I said, "Wait a minute, slow down. What are you talking about?" He said, "They think I have this disease, ALS, Lou Gehrig's disease. I'm going to die."

ALS is not a diagnosis any doctor wants to give. And it's not a diagnosis any person wants to get. Figuring out what to do with this information took a while. It was early November 2008, a dark, dreary, and desolate day in Minnesota. The beginning of what was supposed to be the most wonderful time of the year, and yet the most depressing if you're not into snow, cold, ice, blizzards, and wind. And I wasn't. I just wasn't.

I've learned to trust that gentle nudge from the Holy Spirit, the quiet whisper that tells us when to hold on and when to let go. Sometimes, He stirs our hearts to reconnect, guiding us back to someone in His perfect timing. Other times, no matter how much we long to bridge the distance, He gently but firmly closes the door. Not out of cruelty, but out of love, because He sees what we cannot. And in those moments, as much as it hurts, I've found peace in surrendering to His will, believing that every goodbye is making room for something greater ahead.

Having the ability to gather information and make our own choices was powerful. In that power, we found comfort and peace because of the ability to make a choice. People choose differently. In the end, we decided to give it a try. There was nothing else available, and we could afford it. We were not jeopardizing the future of our boys, and we were not putting ourselves in debt.

We talked about Ronald and how he pursued experimental procedures with his AIDS treatment. We realized, more than ever, how brave and courageous he was in doing that. We never knew the extent of

what Ronald dealt with in going through the treatment. John had a lot of respect for his little brother. That was a special moment.

As John's health continued to decline, we found ourselves having conversations we didn't expect to have so soon in life. Topics covering things like death and dying and wills and estate planning ... and life support. We had hard conversations about his ongoing decline. Things like, "What do we do when you can't talk anymore?" "I can't watch you eat because when you are choking so much, I'm afraid for you." "What do we do when you can't breathe on your own anymore?" Having those conversations with someone you love so much and have been with for so long doesn't get easier. Sometimes the conversations had to be put on hold because it was just too much to process all at once.

There's an acronym that says JOY. It stands for Jesus, Others, and You. I believe that with everything in me. When I shift my focus from *Why is this happening to me?* to *What does Jesus want me to learn?* something shifts. My perspective changes. The weight doesn't disappear, but it feels lighter.

The problem is we put God in a box. Stepping outside the religious or denominational box will allow us to see what God really has to offer. I realized there was so much more to having a relationship with Jesus than head knowledge and going through the motions of what religion expects. I wanted to know more about who He is.

J3 and I had a heartfelt talk about his daddy going to meet Jesus. Thank you, Holy Spirit. It went well and has created a different vibe in our relationship. I told him I would not lie to him and expected the same from him. I shared the stats of this disease. He realized his dad was getting weaker. I told him about the feeding tube his father was going to have. J3 was brave. He cried a little. I told him there was nothing we could do except pray and make Daddy as comfortable as we could.

Caregiving is exhausting; it is consuming. It is thankless, monotonous, and challenging. Yet, giving care is one of the most tangible ways we show someone we love them. And yet, in the monotony of daily activity and caregiving, the responsibility of care is a heavy, heavy load.

I went to the study to look for Dad, who was talking. I asked, "Dad, what are you doing?" He said, "Well, you know, God brought Lazarus back from the dead. Jesus raised people from the dead all the time. He can do it." I love my dad for this, I love his faith. It wasn't that I didn't believe it could happen, but I had reconciled myself a long time before that if God was going to heal someone with ALS, it might as well be John. But it didn't happen. I let him stay in there and wear himself out until he realized John wasn't going to return.

When the boys got home around 6 p.m., we went to the basement and I said, "Your father has gone to heaven." I believe it was Jake who asked, "You mean he died?" I answered, "Yes." And we all burst into tears. I was so sad for all of us, but more for them. I said, "Your daddy passed very peacefully, and he is gone." I told them it was okay to be sad or to be mad. I think we were all just numb.

Why red? Especially when the custom was to wear all black. Honestly, I had never thought of wearing anything other than red. Red is a color of celebration, fire, and force. I was celebrating. And I knew John was too. We were celebrating his release from pain, paralysis, and this awful disease that had consumed him. I was celebrating love, the kind that never fades. Red represents the flame of the Holy Spirit and the fire of faith that refuses to be extinguished. I always thought red was the perfect color for me to wear, and then I discovered red is the signature color of the ALS Association.

Because grief doesn't go away, it changes. It softens. And faith blunts the sharp edges.