A Faithful Kidney Patient Caregiver's Journey

By Sheree Stephens,
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I would describe being a kidney patient caregiver to my husband as inspiring, beautiful, and life changing. Ken has fought kidney failure for years, and I've stood beside him every step of the way. The journey can be, at times, stressful and tiring but with strong communication and a strong relationship with God, the journey is not nearly as overwhelming.

When we met in 2010, he told me upfront his kidneys were failing. I heard him, but love doesn't calculate risks. We built a life together, knowing challenges would come.

In 2016, they did. Ken started peritoneal dialysis, and our world changed.

Peritoneal dialysis impacted our lives, but Ken managed treatments independently. He managed his treatments and care while I kept his supplies in order, assisted with monitoring his health, and, most importantly, lifted his spirits. I moved his dialysis fluids in and out of our home, knowing a hernia could set him back. I sterilized every treatment space to prevent infections. We continued to travel, since we didn't want dialysis to prevent us from living life to the fullest. Thus, we brought his dialysis machine wherever we traveled. I bleached every hotel showerhead and kept every surface disinfected. We wanted to ensure our lives had as little impact from Ken's disease as possible. We were at lacrosse games, school functions, were band booster members, and very involved in our church and community. When we traveled, we traveled by car, plane, and train. Ken's dialysis machine saw Florida to Hawaii and south Texas to Chicago. Ken is a fighter and warrior, and I was right there with him.

After seven years, his body couldn't handle peritoneal dialysis anymore. The switch to home hemodialysis changed our routine, but not our resolve. We learned every step of his treatment. When we completed training, we moved treatments into our home. I started my workday during treatments most days then went into work once treatments were complete. We learned to balance careers, treatment sessions, and living life. We traveled with home hemodialysis as well. Coordination of supplies were a little more involved but easily became our practice. We traveled by plane and RV with our home hemodialysis set up. We wanted to ensure Ken received the best care possible no matter our location.

I learned valuable lessons along this journey and one important one is when to step back. Dialysis is a vulnerable time. A patient sits, exhausted, drained, sometimes frustrated. That time became sacred in our home. No big decisions, no stressful conversations. If stressful family, friend, or work conversations needed to be had, those happened after his treatments were complete and once he had time to recuperate post treatment. Caregiving isn't just about medical support. It's about protecting their peace. I found that protecting his peace and supporting him really was my primary goal. The Lord has protection over our journey. We just stand in the space of doing what the healthcare team trains you to do, peace, support, and grace; the rest will follow.

Caregiving forces you to see what really matters. We never wasted time sweating the small stuff. We cherished every moment and still do. We learned to love the small things: delicious meals, warm laughter, the feeling of holding hands when words weren't enough.

Most importantly, God gave us the Grace to get through it. I believe He led us to Dialysis Patient Citizens (DPC) as well.

DPC's advocacy allowed us to channel our energies to fight for better dialysis care—not just for Ken, but for all dialysis patients. Speaking with legislators and sharing our story became part of our mission.

DPC gave us a platform to tell lawmakers what dialysis patients face every day. Insurance gaps, lack of access to advanced treatments, and workforce shortages. These aren't abstract issues. Rather, they're real struggles that dialysis patients endure. We need to fight to protect them.

Ken received his transplant in August 2024, which was a blessing. Nevertheless, it didn't feel like the end of the battle, the journey of End Stage Renal Disease never ends. The recovery brought its own challenges. Yet, the support we received from DPC reminded me that we are never alone. No caregiver is.

To caregivers out there, know this: you will get through the hardest days. Find a community. Set boundaries. Protect their peace. And most of all, hold on to your Faith.