

Patience and Strength A Caregiver's Journey



By Christopher James, DPC Patient Ambassador

Caring for a loved one with kidney failure requires confronting serious challenges, making significant sacrifices, and

pushing through intense emotions.

My name is Christopher James, and for years I have been a kidney patient caregiver to multiple family members, including my wife, Niesha Neal. Through my experience, I've learned that fulfilling the role of a kidney patient caregiver comes down to patience, perseverance, and love.

My caregiving journey started with my brother, who began dialysis many years ago. With help from my background in biomedical technology, I took on the role of learning how to operate and maintain his dialysis machine. Later, my father developed kidney failure and required in-center treatment, which presented new challenges to his ongoing battle with dementia. Sitting with him during treatments to prevent his confusion and discomfort became a routine part of my life and my brother's life.

Then my wife Niesha was diagnosed with kidney failure. Managing her care at home while raising our children, working, and maintaining daily responsibilities was overwhelming at times. Some days were manageable, but others were incredibly difficult. Dialysis drained her physically and emotionally, and as her caregiver, I often felt helpless. There were moments when she wanted to give up, exhausted by the constant toll of dialysis treatment.

Her journey to a transplant was long and full of disappointments. Over five years, she received six calls for potentially viable kidneys that never resulted in a transplant. Each time, her hope was crushed a little more.

On one bittersweet day, we got news that changed everything. That day, my



mother passed away from her battle with Alzheimer's. On that very same day, Niesha was told that a kidney and pancreas were available for her. The emotional weight of joy for Niesha and sorrow for my mother was difficult, but ultimately, Niesha's successful transplant marked a new beginning for us.

Our journey brought us to Dialysis Patient Citizens (DPC) to advocate for better support for kidney patients and their caregivers. One of the biggest challenges many families face is the gap in insurance coverage between diagnosis and when Medicare or Medicaid benefits begin. I saw firsthand how this financial burden affected my brother, who lost his insurance after his kidney failure diagnosis, leaving him struggling to pay his bills. I even lost my job due to the amount of time caring for Niesha, presenting complex financial difficulties. We must push for policies that ensure

all patients receive the care they need without added financial challenges.

To fellow caregivers, my message is simple: You are not alone. The road can feel isolating, but support exists. Seek out caregiver groups, connect with medical professionals, and take care of yourself. I found that even brief moments of meditation helped me reset when the stress felt too heavy. Accepting that things often won't always go as planned made a big difference in my mental health.

Most importantly, remember that your efforts matter. You are a lifeline for your loved one.

Today, Niesha and I continue to advocate for kidney patients, sharing our story to help others navigate their own journeys. Caregiving is never easy, but through support and advocacy, you can make a difference!