

Patient Testimonial: My Experience with Polycystic Kidney Disease



My name is Ellyne Dombro and I have polycystic kidney disease (PKD).

I was diagnosed 27 years ago when I was pregnant with my son. Being told that you need to go on dialysis can be a scary time. I did not know anyone who was on dialysis who I could talk to.

My nephrologist and nurses told me about peritoneal dialysis (PD) and in-center hemodialysis. In-center hemodialysis would require me to go into a clinic three times a week and also get a fistula – all of which I did not want to do. PD sounded like something that would work better for me because of my work schedule.

After further research to see which option would be better for me, I decided to pursue PD as my treatment choice. I have been on PD since June 2016. PD allows me to continue working during the day while I do my dialysis at night. When I first received training, it felt like opening an algebra book after 20 years of being out of school. I thought, “I can’t do this!” At first, training was overwhelming, but with the help of the training nurses, I was able to overcome my fears and anxieties. It only took two weeks of training for me to get comfortable. My training nurses showed me step-by-step how to connect and disconnect from the cyclor. They also taught me how to prevent infection. At the end of my two weeks of training, I was able to use the cyclor machine at night, disconnect early in the morning, and go to work. You can say I am a pro at it now! I am seen once a month at my clinic to go over my labs and discuss my care with my nurse, nephrologist, dietician and social worker.

In December 2019, I had a nephrectomy (removal of kidneys). Due to abdominal healing, I needed to take a break from PD for a bit. Therefore, I was on in-center hemodialysis from December 2019 until February 2020. Although my experience with in-center was excellent, I switched back to PD dialysis in late February 2020. PD gave me the flexibility to do my dialysis at night as I continued to work during the day. Overall, I feel okay with PD dialysis. Some patients prefer home hemodialysis. We have to make the decisions that will be best for our lifestyle.

Being on PD has given me the opportunity to share my experience with other dialysis patients who may be thinking about home dialysis as their treatment choice. I recently started a support group in my facility where PD dialysis patients and our in-center patients come together to

share experiences and challenges. It has been very helpful and rewarding to hear from other patients who are going through similar experiences. As PD patients, we can answer questions from in-center patients about our home dialysis practices.

I am happy to say that after a very thorough diagnostic workup, I was added to the kidney transplant waiting list at the Hospital of the University of Pennsylvania in 2013. I am also listed through Virtua-Lourdes and Johns Hopkins. Each year an evaluation is requested by the transplant team to make sure all tests are current as I wait for a kidney offer.

For more information about peritoneal dialysis (PD) and other treatment options, please contact Quality Insights Renal Network 4 (QIRN4) by calling (800) 548-9205 or visit our website at www.qirn4.org.