

Treatment Options

Overcoming Treatment Option Challenges: "Everything is NOT for Everybody"

by Ron Colbert, Patient Subject Matter Expert, PAC Member

I have used every treatment option for my end stage renal disease except transplant, (I am hopeful that will happen soon). I have done nocturnal dialysis (8 hours at night in-center), dayturnal (8 hours in-center during the day), home hemodialysis and PD. PD was the least successful option for me; however, there are many people that have good outcomes on PD.

I am going to share my experience with Peritoneal Dialysis (PD). First of all I have been on dialysis for 7 plus years. My motto is "I do dialysis to live; not live to do dialysis." That said after 4 years of in-center dialysis, I decided to try home hemodialysis with the NxStage machine. After approximately a year at home, I had to return to in-center dialysis to get antibiotics due to an infection in my arterial buttonhole access.



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I am a 54 year old father of three adult children, a daughter-in-law and two grandchildren, and have a degree in Speech Pathology/Audiology.

A family history of diabetes and kidney disease are in my genetic make-up; twenty years of diabetes, coupled with seven years of dialysis resulted in me having three amputations.

I spent most of 2015 in the hospital, including a month in the ICU resulting in a left leg BKA, in February; a right leg BKA in June; and a right leg AKA in July 2015.

Throughout all of this, I maintain a positive outlook, drive myself wherever I need to go, have good labs and no current infections, therefore, I am anticipating getting a transplant soon.



I had a wound vac over the arterial buttonhole part of my access, but was able to continue to use the access to dialyze. As my home health nurse changed out the wound vac, I experienced an arterial hemorrhage. The nurse called 911, the paramedics placed three tourniquets on my access over my objections, saying they "must preserve life." I was taken to the emergency room and of course the bleeding had stopped. In the process of stopping the bleeding, my access clotted.

I was told I could no longer have an access in my left arm and that my surgeon would have to put one in my right arm. At that time I opted to give PD a try, thinking I would still have the freedom and outcomes I had experienced on home hemodialysis.

Well, "everything is not for everybody." After PD training, I realized that my body size (6'2", 250lbs) meant that my therapy required that I be hooked to the PD cycler for 13 hours every night.

Even with such a long treatment time, the

therapy was taking off the fluid but was not cleaning my blood. I became very ill, and consequently became too sick to even connect myself to the cyclor. I called 911 and was taken to the emergency room.

Due to the loss of my fistula, I could no longer do home hemodialysis, and due to the complications that I had I was only able to do PD for one month. After a second opinion from the Access Center Nephrologist, I now have a left forearm fistula, and I am doing in-center hemodialysis (5 hours per treatment) as I anxiously wait for a transplant.

So if you are considering PD as a treatment option, consider these things:

1. Your muscle mass, large frame individuals' may need more dialysis, which could lead to much longer CCPD (Continuous Cyclor Peritoneal Dialysis) treatments or more frequent CAPD treatments, or a combination of both – which could mean round the clock PD.
2. The cyclor is hooked to a catheter through your stomach and is always present. As a single person, I felt this was intrusive and not something I wanted to explain when it came to dating.
3. PD requires a lot of supplies and a lot of storage space (My apartment was small, and the monthly supplies took up a lot of space (my clinic did not offer bi-weekly supply deliveries))
4. The infection rate for someone during PD is high. Ask about infection rates nationally and at your clinic before making the decision to do PD. (you can use Dialysis Facility Compare at medicare.gov/dialysis to look up dialysis clinics, or speak to the staff at your clinic)
5. Finally, PD requires time and dedication, especially with CAPD which requires you to perform several exchanges during the day.

Resources:

To learn more about finding a treatment option that works for YOU, please speak to your health care team, contact the network or visit these websites:

The Renal Support Network:

<http://www.rsnhope.org/dialysis-options/>

My Dialysis Choice:

<http://mydialysischoice.org/>

ESRD National Coordinating Center:

<http://esrdncc.org/patients/treatment-choices/>

About the Patient Advisory Committee (PAC):

The Patient Advisory Committee, through its representatives in dialysis and transplant units, provides a link between patients and unit staff and opens opportunities for Network area communication for those in the renal community.

To become a PAC Member or Patient Subject Matter Expert (SME) please contact the IPRO ESRD Network of the South Atlantic: (800) 524-7139 or visit our website: esrd.ipro.org/PAC

To file a grievance, please contact us:

IPRO End-Stage Renal Disease Network of the South Atlantic
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