When You Have Lost That Loving Feeling: Sex and Intimacy on Dialysis

By Erich Ditschman

"Well, hello, Mr. Ditschman. How is your sex life?"

This is one greeting I have never heard in my dialysis clinic. Okay, well maybe by Michael in the waiting room. And yes, I did blush. But, I never heard this once from my doctor, nurse, dietitian or social worker. In my 17-years on dialysis, sex has not been that big of a concern for my medical team, certainly not as big as keeping me alive.

If you check out your dialysis clinic's website, you will probably find a link near the bottom of the page to a "Sexuality on Chronic Kidney Disease" page. Here you might be reminded that you have been too busy trying to adjust to your new normal of dialysis, while trying to take care of your family, work and finances, to think twice about sex, let alone once about intimacy. If this sounds familiar, but if you are not



quite sure of the difference, here is a quick refresher. In a recent DPC Education Center webinar, David Spero described sex as physical contact that brings pleasure, excitement and connection. He stresses that sex is not limited to intercourse nor the use of genitals at all. He describes intimacy as contact (not necessarily physical) that brings closeness, safety and love. See accompanying box for a list of sex and intimacy benefits.



For me, I could not focus on any of that until I found a part of myself that I could recognize. I needed some light to pierce the forest of fear in which I was lost—a glimmer of clarity from which I could convince myself that I could do this dialysis. In the beginning hope is transient, like the sun peeking through a dark cloudy day. Just as the sun brings relief and a smile, hope makes us persevere.

Like many, I initially crashed into dialysis. One day, I was working, finishing a graduate degree, and enjoying our one-yearold son with my wife. Then three months later, a central line was placed in my chest. Soon after, once many of the toxins had cleared, my social worker brought a man with a fistula to my chair. My vanity said no way. My body would never look normal again.

It was not until five months later, after the kidney I named "Annie," donated by my wife, failed, and a fistula was placed, and memories of my once prominent libido flickered in my dreams. But with three times a week treatment, I still felt consumed with dialysis. Any energy I had was devoted to my family. As I settled into a routine, I felt stronger. On some days, I even rode my bike to the dialysis center a mile away.

Still, it did not occur to me to bring up the subject of sex and intimacy to my team. I was not quite there. Perhaps one of the reasons my team had not brought it up was because the topic has not been well studied. In his recent review of literature related to male sexual dysfunction and kidney disease, Matthew Edey points out, "Historically, this cause of considerable morbidity has been under-reported and under-recognized." A similar observation can be made for female sexual dysfunc-



tion and kidney disease. This is confirmed with a simple Google search. See the accompanying box for potential causes of CKD Sex Problems.

Eventually, the following things occurred which finally brought the desire for sex back into my life. I stopped acting sickly. I took control of my treatments. And, I became the leader of my medical team. It was

Health benefits of sex: helps with sleep relieves pain is a mild form of exercise improves system functionlowers blood pressure

Life benefits:

improves self-defined quality of life raises self-esteem improves relationships and intimacy motivates self-management provides emotional support/comfort

Source: David Spero, Sex and Intimacy with CKD, The Dialysis Patients Citizens (DPC) Education Center (http://www. dpcedcenter.org/sex-and-intimacy-ckd-recording-nowavailable), 2017.

Causes of CKD Sex Problems Vascular (blood flow vessels) Endocrine (hormones) Neurologic (nerve damage) Pharmacologic (medicine) Anemia (blood volume) Hyperparathyroidism (hormones) Psychologic (depression)

Edey, M. M., Male Sexual Dysfunction and Chronic Kidney Disease in Medicine (http://journal.frontiersin.org/article/10.3389/ fmed.2017.00032/full), March 22 2017, pp.1-32.





not until I experienced the stability of regular in-center treatments that I began to grasp the reality that dialysis was my gift of life. I came to an understanding that additional kidney transplants may or may not be in my future, and that I had to stop being a patient waiting for a cure. I had to start living my life fully each day, while riding the crazy roller coaster that is dialysis.

My wife and I will be celebrating our 30-year wedding anniversary in January. She recently reminded me that from her standpoint intimacy was hard because most of the time I was unable to share closeness, not sex, but just being emotionally close. She noticed that when I was not dialyzed well, or anemic, that I was unable to be present. She also had concerns with touching my fistula and whether I might have a heart attack if we did have sex.

During in-center treatments, I started researching home hemodialysis using a 70-lbs. portable dialysis machine. I found a center about an hour away from home where it was offered, and my nephrologist agreed to re-credential so I could try it. The hardest part of training for me was learning to stick the dialysis needles in my fistula. But that was my ticket home. I am generally a fainter, but I thought about my son and our then one-year-old daughter, and how I needed to be there for them. So, I pushed the needle in and somehow, unlike the many techs and nurses at the clinic, I poked it perfectly. Sure, there was pain. A few years after, when I replaced my fistula with a graft and could no longer use the tunnel technique, I experienced pain when I poked where there was no scar tissue. I occasionally do still. But, this pain reminds me that I am in control of my treatments and I am no longer a patient, rather just a guy who has a glorified toilet at his bedside, my dialysis machine. I give dialysis about as much thought as when I used to lift the lid and pee–and, of course, then shut the lid. The switch to more frequent dialysis at home was a game changer for my libido. I really had not realized what I had lost until I started daily dialysis. I even wrote the President of the dialysis company and told him that his machine was better than Viagra. My wife noticed the difference too, reminding me that by being better dialyzed, I felt better and had more energy.

I used this energy to pay more attention to her. I had the strength to give her back massages and to take on more responsibility at home. For the past number of years, as our roles have changed, I have taken care of the grocery shopping, and try to make sure we have a tasty meal when she comes home from work. I recently took her on a surprise vacation for her fiftieth birthday. These are the things that lead to intimacy in our relationship. And, with intimacy comes physical connection.

I no longer wait for my team to approach me about sex and intimacy. As the leader of my medical team, I started the conversation. When my physical ability could not keep up with my desire, I asked my nephrologist about Viagra. After attending a dialysis patient conference, in clinic I asked my social worker about vacuum pumps and implants and whether or not they are covered by Medicare. Both Medicare and private insurance companies cover these treatments. And, yes, I had to get over the fact that many on my team are women. I mean what was I going to do, ask my wife to ask for me?

My dialysis team still does not ask me about my sex life, but I give them an answer anyway. It is getting better all the time.