Work, Life & Sex After Transplant

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Good afternoon, distinguished guests, ladies and gentlemen. I am honored to be attending TTS this year as a survivor of renal failure and a kidney transplant.

Before I begin, I want to thank each of you personally for being here and for being engaged in these conversations. What you do each and everyday matters to families like mine. It is deeply personal.

I come from a family of women who are genetically predisposed to have polycystic kidney disease. I have lived through two generations of transplants, starting in 1986 when my mother received her transplant. Two decades later, I had mine in 2008, and nine years after me, my sister had hers in 2017. My niece will likely need a treatment option in the next couple of decades, and it's highly probable one of her 3 children will too.

Like I said, this is personal for me.

So when TTS asked me to speak about Work, Life and Sex after Transplant, I thought, "Really? Sex?" But then I jumped at the chance because how else can we expect to make significant changes in the care of transplant recipients if we aren't talking about the issues that they will face AFTER the transplant?

When someone needs treatment, it's easy to focus solely on how to treat the problem. But we rarely think about what happens next, the ways in which a transplant will not only extend your life, but the myriad ways in which it will alter all aspects of your life.

As a 15-year transplant survivor and ardent patient advocate, I am honored to be a part of that change, which may begin in this room, right now, and could positively shift the way we train medical staff to care for all transplant recipients, especially female patients.

Which brings me to the 1st topic of work:
I have had a great career as a Technology Leader for over 35 years before I semi-retired in 2022. Before the age of 20, I was already anticipating a future of huge medical bills so I often worked 2 jobs to save enough money "just in case." In some ways post-transplant, I still felt that guilt of needing to "earn my kidney" and

continued to show it by working extra hard, saving for the day when my donated kidney would inevitably fail.

Now in terms of dating and sex, I was married for 8 years before my transplant. As my kidneys began to fail, I had barely enough energy to go to work, so sex basically stopped. I was very self-conscious of the halitosis so kissing basically stopped too. My husband had a hard time dealing with my declining health and we divorced a year before my transplant. That’s right, HE had a hard time with it. Thankfully my transplant outlasted him.

So I stand before you not just as a survivor, but as a better version of myself than I could ever have imagined… with some caveats.

You see, the road to get where I am now was extremely bumpy but didn’t have to be. Let me explain.

As a woman who is intimately familiar with the healthcare systems in both Canada and the US, I feel extremely qualified to speak about the treatment of female patients, which can be condescending and uncomfortable. As you can imagine, the process of kidney failure is bad enough. But throw in the casual nonchalance of a well-meaning but checked-out medical professional, and instead of feeling more secure and comfortable, I felt unseen, unrecognized, unheard and misunderstood.

Since I was diagnosed at age 19, I have predominantly seen a male nephrologist. As a female with renal failure, the focus over the years tends to be on my lab results. On many occasions, I have been talked down to… rarely have I been asked questions. I’m now four decades into my diagnosis, and I can count on two hands the number of times a doctor has made sustained eye contact with me.

Oddly I thought this was the standard of healthcare because I had no frame of reference to the contrary. If someone is not willing or comfortable enough to make eye contact with me, how comfortable do you think I feel asking about sensitive health issues like menstruation or my sexual health?

With that, let’s step back to when I received my transplant in 2008. I was on a cocktail of Prograf, CellCept and Prednisone…

…on the rocks
…no salt rim

I had been told about side effects but frankly, I was so focused on recovering from my surgery and getting on the lowest doses possible that I hardly heard them. Sure, there were physical signs – like hand tremors, excessive hair growth and the notorious moon face – but I had no idea what was lurking in the background.

Fast forward 10 years to 2018, when I started having abnormal pap smears. I underwent 2 LEEP procedures 6 months apart to remove HPV dysplasia from my cervix. Let me describe what the process feels like: imagine taking a set of tweezers and pinching your genitals repeatedly. It is painful, physically and psychologically. Sitting at my desk job the following week was deeply uncomfortable, PAINFUL….but I had so many transplant-related appointments, I could not afford to take days off to recover.

This is what work was like post-transplant for me. I prayed not to get sick, and for the pain of my vaginal procedures to be bearable enough that I could work at my desk. Sick days did not exist so I either used my vacation days or worked extra hours unpaid to have time for all of my medical appointments.

Then, in 2019, the dysplasia returned, only this time it also spread to my colon. I was advised I needed a joint vaginal and anal surgery. Oh, and there was also a recommendation for a full hysterectomy. They wanted to remove my entire uterus!!! Naturally, I was terrified and I asked if there were other options.

The answer from my team was a curt “no.”

Instead, my medical teams questioned my sexual practices, implying that my sex life was the root cause for the cancerous return. I cannot stress to you how humiliating this was --- especially when I hadn’t dated in years.

As a side bar, I can tell you that most men are not keen to date a woman with a chronic illness, let alone when you tell them you have had cervical cancer.

You may not know me, so maybe this doesn't feel personal for you. But imagine that your mother, sister, wife or daughter has survived a transplant AND several uncomfortable cervical procedures … and still her cancer returns. In that time of great worry, would you be okay with her sex life being called into question?

However, through this process, a curious thing happened. The less my practitioners listened to me, the louder my inner voice became and the more I listened to myself until someone else heard me.

In 2020 when COVID was rampant, my gynecology care became a lower priority for a year and a half. Then, in early 2021, I was told I needed another surgery. This time, I was the one who said "no." By then, I had sought out other expert opinions and they confirmed what I believed - CellCept was the main cause of my HPV and cervical cancer. I gathered my siloed team – GP, nephrologist, ob/gyn, anal surgeon, infectious disease, therapist – and told them I wanted to get off CellCept.

I would do my part and quit my job, get labs whenever they wanted and focus simply on healing. It was risky and most did not agree, but I persisted, and they LISTENED. Six months later, no signs of HPV were present much to their disbelief. Three YEARS later, there are still no signs.

Since then, my kidney function remains stable on my 2 ingredient cocktail of Prograf and Prednisone,

still on the rocks,
still no salt rim

Listening to my inner voice and advocating for my own life saved me from a hysterectomy and quite possibly from dying…from the side effect of an immunosuppressant.

I endured years of unnecessary invasive procedures and surgeries along with expensive medical bills to convince my medical team that there was another root cause and a solution.

There are numerous studies that highlight the CellCept HPV and cancer risk by Yusuf, Shae, Kempen to name a few. Yet I know MANY women today who still undergo repeated LEEP procedures, or had hysterectomies because rather than being proactive, their transplant teams tell them to see their ob/gyn because (quote) “HPV is not transplant-specific.”

So this brings us to where I am today.

Well, as you know, I quit my job two years ago to focus on my health, which led me to move to Costa Rica. Since then, I have focused on consulting projects that inspire me and ignite my passion for patient advocacy and true integrative healthcare.
I’m not only alive, but I am thriving. I feel called to live a purpose-filled life and to be in spaces like this one in order to create change for patients and practitioners alike.

As for dating and sex, I will be honest - it is still not easy. As the years of my transplant increase so does my mortality, which is a concern for men I meet. One study by Glantz saw a higher rate of women with serious illnesses being abandoned because men are less likely to take on the caregiver role. Personally, I feel how to navigate a chronic illness as a single woman is not talked about enough - yet should be.

In fact, when I packed up my life, sold my house in California and moved to Costa Rica, many people thought I was crazy. With my health concerns, it seemed risky to move to what some call a 3rd world country.

But you know what? In Costa Rica, I have had the best health care to date.

Do you want to know why?

I see far fewer and more integrated healthcare practitioners, reducing the amount of coordination I have to do as a patient. Each specialist I see spends at least 15-20 minutes LISTENING to me. They want to know about my life, what makes me happy, how my Spanish is coming along, how my mental health is, what concerns me. They maintain eye contact and do not open a computer or lab result file until we have this conversation. When they actively listen to me, I feel like a person. I feel validated. I feel seen. I feel like I’m an active member in my own care.

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This is a secret to my wellness, and I believe it is also a secret you can use to improve your practice and your patients' lives after their transplants. Whether you ask and listen about their personal and family life, work, hobbies, menstrual and sexual health, mental health… you can help normalize the conversations -- especially around those hard to talk about subjects. You can help them achieve a happier life post-transplant by hearing their concerns and validating their humanity.

I'll say it again: Listen. Actively listen to your patients. Make them feel heard and understood. It is as powerful as a drug, and it will be a game changer for both of you. I know you also will have more compliant and thriving patients. You will actually attract more raving reviews.

You have the ability to LEAD and BE the change we need in healthcare.

I will be at the Women In Transplantation 15th Anniversary Celebration Happy Hour this evening and I hope to see you there so we can continue this conversation

perhaps with a cocktail
…on the rocks
…no salt rim

THANK YOU FOR LISTENING!

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