

Soania Mathur – patient extra transcript

Soania 00:35

My name is Dr. Soania Mathur and I was diagnosed with Parkinson's at the age of 28. My symptoms began as an intermittent tremor in my right pinky finger, which was really more annoying than anything else in the beginning. A little bit medically intriguing actually, considering I've never felt what a tremor was like. But it became more constant and concerning in my right hand and then sort of spread to my right foot, and then my left hand and my left foot. So, it became a much more prominent symptom than it started out as.

Soania 01:27

At the time I was diagnosed, I was actually just completing my residency in family medicine. I was about to open my own clinical practice. And I was expecting my first of three daughters at that time, so not the most convenient time, if there can ever be a convenient time, but it was certainly a busy time of life and I was at my prime.

Soania 01:55

I reacted with disbelief in a lot of ways when the first neurologist told me that he thought I had young onset Parkinson's disease, I thought he was wrong. But I did accept his offer for another opinion from a movement disorders specialist, who I still see to this day. And he decided to confirm the diagnosis, which was a difficult thing to accept at the time. I sort of lived in denial and fear and despair for quite a number of years following my diagnosis. Although I had intellectually accepted it, I hadn't emotionally accepted the diagnosis at that point.

Soania 02:41

My path to becoming an advocate took a little longer than I think for most people. When I was first diagnosed, I, as I mentioned, I was sort of in denial and fear of my future. And began to recognize that living in that kind of headspace was not a healthy way to be. I was becoming a person that was more pessimistic, focused on the glass being half empty. And that wasn't really where I should be, considering I had three beautiful daughters, a loving husband and a career that I absolutely adored. So I, it sort of it wasn't after any one conversation, or any one thing that I read, but I began to slowly realize that I didn't have control over my diagnosis, I couldn't just wish it away. It was here to stay for now. But I did have a choice in how I approached the diagnosis and the challenges that have brought into my life. It was actually not an easy choice, but my choice to be optimistic about the future. And that's where it slowly started to change for me. And then once I stopped medical practice because of my symptoms, I turned to advocacy for patients in this community and education and, you know, basically trying to advocate for changes to be made that will better the life of people living with this disease. I have had a great amount of support, I would say. For me, as I mentioned, it took a good 10 years before I really began to accept my diagnosis. And until that time, I hadn't disclosed to my wider social circle, or my patients or colleagues that I worked with, mainly because I didn't want a pity party that I thought would ensue after coming up with a diagnosis like this, but instead there was an outpouring of support. I have a very loving family, husband who's also a physician, extremely supportive, and three children that

have grown up with me always having had the diagnosis. And at first I thought that would sort of bring about some hardships to their lives and I'm sure it has, you know, troubled them from time to time. But they've grown up to be very empathetic, caring individuals with compassion and recognition that life isn't perfect, but how they face their lives will determine what kind of people they end up being. So it's actually been a learning experience for my family as well. But in general, I've had a lot of outpouring of support. And if I had known then what I know now, I would have probably disclosed a lot sooner, but it's a very personal decision for everyone to make.

Soania 05:30

I've been living with Parkinson's disease for 23, almost 24 years now. And my symptoms have obviously progressed during that time. They've gone from being primarily tremor dominant to a lot more non-motor symptoms, I would say. So the tremor is obviously still there, when I'm not medicated, the stiffness, the slowness of movement, the postural instability, I'll have all of that. But I also experience some anxiety. Some other issues like swallowing difficulties, constipation, urinary urgency, a lot of pain and sleep disorder as well, where I don't sleep very well or very soundly. This disease is encompassing, it encompasses it affects you mentally, emotionally, and physically. So it's a very pervasive disease that way.

Soania 06:30

There are two parallel tracks, the research has to continue to find better treatments and ultimately a cure. We need disease modifying drugs, drugs that can actually attack the pathology of this disease. But we also need to make sure that we care for those that are living with the disease now and advocate for their ability to live well, as well as possible with this disease, to optimize their quality of life. I think we have to address that community need as well.

Soania 07:03

When I stopped medical practice, I thought I would be bored. That was my biggest fear, that I would be bored with my life because I was so busy beforehand. Unfortunately, or fortunately, I guess I'm probably busier now than I was, but it is, I guess my own schedule. I spend a lot of time on writing, I spend a lot of time speaking at different events for different community support groups or Parkinson's organizations. I sit on a number of boards. It's a disease that shadows you every second of the day, and now shadows me during work as well. But it's my life passion, though. It's a choice that I'm glad I made at the time that I made it, after my clinical practice was done.

Soania 08:06

Someone living with Parkinson's disease that may be just newly diagnosed may feel very isolated, I think we all do at the time of diagnosis or, as a care partner may be very frustrated or scared about the future as well. And they're not alone. There's a huge community of very supportive people that make up our Parkinson's tribe, I guess, and are always available to help out in any way. You also have to take active management of your disease, either as a patient or a care partner. You can't live passively and expect to live well with this disease. Take charge of your illness, assemble a medical team or Parkinson's care team that has your best quality of life at heart and at the forefront of their mind. And continue to do everything that's within your power to control those variables that you do have control over, like your self-care, your sleep, your nutrition, your stress level, and avoid socialize isolation at any

cost as well. So there's lots that we can do to take control over this disease and optimize your quality of life. And until there's a cure, it's all about quality of life. Understand that you may not have a choice in terms of the diagnosis but you do have a choice in terms of how you face the challenges that this disease brings.