

My story of living well with Parkinson's

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Abstract

Each person has a different story to tell, this is my own inspiring story. Some are diagnosed immediately, some take years, some with the medications. Each one's Parkinson's is as unique as his fingerprint. Symptoms vary with varying progression. But all of us fighting the same battle. Once diagnosed you take one of the two paths either you give up and do nothing or accept & move on and make a difference. I chose the latter, I call myself a warrior, we all are, fighting every second every minute every hour every single day. "Do not go where the path leads But go where there's no path and leave a trail". Early 2011 loss of swing movement of my right arm noticed by my son and husband. I first ignored it and after a few months not able to slide my right leg into my slippers that's when I sought medical help. I was referred to a neurologist who gave the diagnosis of YOPD. But I couldn't believe it and I went to another doc who gave the same diagnosis. But with no family history, the first thought was why me? I was 36 years old and to put this in perspective for you - YOPD affects about two to 10 per cent of the one million people. It felt like I'd been cheated out of my perfect life. My doctor prescribed medicines and told me to come back after 6 months. And with this very little information and support, my quest began to understand YOPD. In the beginning, it was about how to cope with this illness, Did I need to change my lifestyle or diet? Were there support groups out there That I could rely on? This endeavour to cope made me realise how little there was out there in terms of resources, information, help or support. This is not just for YOPD but for all Parkinsons' and even other neurological disorders. Everywhere I looked there was a dearth of support and resources. More importantly, there seemed to be a taboo around talking about it at first devastating shocking kept asking the question myself why me? Then I started reading about famous people with Parkinsons Mj fox, Mohamad Ali and how exercise delays progression. I started a fitness regime, kept myself active but didn't reveal my PD to other than next of kin. The year 2018 was the turning point in my life. I stumbled upon the opportunity to take part In Mrs Internations pageant held in Singapore. A life-changing experience. It was different and difficult competing with normal people especially while preparing for it. Every round was a challenge had to time medications according to the rounds, fight fatigue, wearing heels, but I was determined that Parkinson's will never ever take over me. I won the title, most empowered woman 2018-19 and I realised my purpose here on earth. when I came back to India I started my Instagram handle "shake_off_and_move_on" and April last year my foundation. Here is what I did to live well with Parkinsons. The below are some of my personal practices which helped me stabilise me mentally and physically however this information posted here is not to be considered as any sort of medical advice and is not intended to replace consultation with a qualified medical professional.

Biography

Shantipriya Siva is the Founder and CEO of SAAR Foundation, India.

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