

Engagement is my key to wellness with PD

Getting a [Parkinson's diagnosis](#) is a sobering moment, but fear and backing away from what worries us never works in the long run. What's sobering, or frightening even, is the uncertainty about what it means to have a progressive, incurable, movement disorder. Will I be unable to run? shuffling along soon? unable to drive? mute? When does all this start happening? Answers to those questions still linger, but after a few deep breaths it became clear that these worries were not going to be faced, say, next week. The most immediate challenge was to convert all this external tremor and internal commotion into some kind of new normal so that I could get on with the business of living well. *The key to moving forward has been engagement.*



Engaging with the exercise community

I was engaged with a local trail running community for more than a decade prior to my diagnosis in late 2021. There I learned a lot about the value of building friendships outside of my professional field and age group. Weeks after my diagnosis, I connected with one of the [Davis Phinney](#) ambassadors who urged me to start weight lifting to add to my routine as a trail runner. So off to MVP I went where I have met a few others with Parkinson's and made new friends without Parkinsons who are lifting and moving for the same reason as me: to improve their quality of life. Having no experience lifting weights, the six personal training sessions I had with Daniel Call were invaluable. Daniel taught me the fundamentals, good form, how not to get hurt! He also had an amazing intuition about the brain body connection that he talked about in ways that made me think differently about my exercise. Daniel said, "Dan, you are already strong" and

that inspired me to get stronger! I met Cathy Rink through the Well-Fit Move class, a near perfect complement to the lifting and running I was doing on my own, and because of the comprehensive focus of that class on balance, strength, and agility, it's a perfect design for persons with Parkinson's disease. As my second personal trainer, Cathy taught me to integrate crossfit style movement as part of my exercise routine. She remarked at the end of our weekly meetings together, "Dan, your Parkinson's really doesn't have to limit you in any way at this point." A positive prospect like that has inspired me to stay positive and have high expectations of myself. And I have not abandoned trail running, which now includes my neighbor's dog Khloe, one of my greatest friends and supporters.

Engaging with friends

Being known by others is the essence of friendship, and friendships are one of the foundations of happiness and purpose and meaning in life. Letting friends in on this new development in life has been a constant source of support moving forward. The support of friends and family provokes the ineffable experience of being known for who you are, and this now includes my private experience of the irritating tremor or the latest non-motor symptom. Being open about my Parkinson's diagnosis has required transparency with friends in order to be known and move forward living well.

Engaging with the care team and the PD community

I live in Grand Rapids, Michigan where I have access to Corewell Health's Parkinson's multidisciplinary team, a program that the Parkinson's Foundation has designated one of the first Comprehensive Care Centers in the U.S. I feel lucky. This Care Center has served as a gateway to new friends and other communities formed by people with Parkinson's. The care team invited me to join the PD advisory council to provide a new-patient perspective as we make efforts to grow and improve the multidisciplinary program. The care team has also urged me to help facilitate discussion in our monthly educational meetups, putting to use a skill I developed in the many years I spent teaching at a university.

Engaging with the research community

After these few deep breaths, I decided to participate in a clinical trial. As a participant in a year-long trial, I met a gentleman, another "human subject" like myself, who told me about Jon Palfreman's *Brain Storms* (an excellent history of PD research) and about the annual Grand Challenges conference at the Van Andel Institute where I live in Grand Rapids, Michigan. At that conference, I met medical professionals, graduate students, clinicians, and others doing scientific research on Parkinson's as well as some of the staff from the international Cure Parkinson's foundation in London. The clinical trial and each of these relationships has become a source of inspiration and engagement.

Remaining open with friends (and dogs), learning from the resources provided by medical professionals, participating in research opportunities, and leveraging the opportunities afforded by local exercise groups, these four sites of engagement have provided me with the meaningful support and diverse learning and social opportunities needed to live well.

Engagement has been my key to *leaning into* this sobering diagnosis.

April is national Parkinson's awareness month. To learn more about Parkinson's disease, a progressive movement disorder, visit the [Parkinson's Foundation](#).

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