

PROLOGUE - The Parkinson's Prison

"I'm a prisoner in my own body."

-- Muhammad Ali

"The last of the human freedoms: to choose one's attitude in any given set of circumstances, to choose one's own way... a decision which determined whether you would or would not submit to those powers which threatened to rob you of your very self, your inner freedom."

-- Viktor Frankl, *Man's Search for Meaning*

The Parkinson's prison is a relatively new idea that emerged from research in the final semester of my PhD program. As with all new ideas, there's a shaping and discovery period where no one, including me, as its creator, knows exactly what it is. That's fitting because there's a lot of unknown in PD, too. Here's a working definition to get us started: The Parkinson's prison is a crippling mindset, story, or series of stories that can manifest in the form of self-imposed limitations. These limitations can occur for those living with PD, their care partners or family members, and those treating it. For example, a doctor who says with absolute certainty what will or won't happen to a person with PD upon diagnosis: you won't be able to drive, you'll be in a wheelchair, you better get your affairs in order. All of these statements may be "true", technically, but that doesn't necessarily make them helpful at the moment of diagnosis. There is an understandable emotional response to receiving a PD diagnosis. The doctor must listen carefully to give the person diagnosed a chance to understand what they are feeling. There is no right or wrong way to feel. It's complicated, often shocking and traumatizing. The space to allow this to be unpacked at the diagnosis, unfortunately, is relatively rare. Whether it's lack of skill, time, compassion or training, many people with PD report their diagnosis being presented in a cold, stark, and matter-of-fact manner. This can leave them feeling abandoned and imprisoned in the worst, end-case scenario of the disease as if it were happening today. And, for many, that feeling of being overwhelmed results in denying or trying to hide their diagnosis.

Here is a story from John, a person with PD, about his day of diagnosis: "I felt numb as I left the doctor's office and returned to my car. It was raining lightly. I sat in the car without turning on the engine. What now? I knew there was no cure, nor any proven way to stop the progression of the disease. I felt fear for my future. How much longer could I work? How would it affect my marriage, my relationships with family and friends, my ability to be active in the world? There were no clear answers."

As bad as the initial diagnosis can be, the following descent into Google Hell is often worse. Go on, Google "Parkinson's disease" and see what you get. Click on the images tab. See the old, hunched over white man? That's the representation. That "is" PD, even if it doesn't align with the person who was just diagnosed, because that's the story they start to tell themselves: "*That's me.*"

At the point of this writing, there's no answer for why anyone gets PD. The term used is "idiopathic" - which means "of unknown origin." No one knows exactly what will happen with a

PD diagnosis, which symptoms you'll get, which you won't, at what level, when they will present or at what rate the disease will progress. If a diagnosed person takes their medication, exercises and engages socially, PD tends to be considered to be a slowly progressive disease...but that's subjective, too. However, if a newly diagnosed person buys into a specific piece of the narrative, especially handed down from their doctor, a person of authority, they can lock themselves up with an insidious laser focus on only what is *not* possible. "Can't" or "Shouldn't" all too often rule the day. The loss, pain, fear and vision of the hunched-over person needing help right now as their present-selves, and not as their future selves, can take over. Their power, which consists of doing what they can in the given moment, is handed over to a false, imprisoning narrative. They are trapped as characters in this self-penned tragedy. The acceptance of only the worst parts of the disease, combined with the fear of "what comes next?", including the anxiety, stress, depression, stigma and shame that are all too often associated with it, can lead to isolation and even a tragic, premature death.

If you're reading this and thinking, this isn't just about PD, you're right. We're all subject to imprisoning ourselves or others in limiting belief systems and stories handed down by power structures and individuals within institutions (family, schools, medicine, government, etc.): "You can't," "You're not smart enough," "You're too weak," "You'll just screw it up...again" and so many more. Though PD is my area of focus, I encourage you to lean into these ideas and apply them as you see fit.

My pathway to these understandings in relation to PD came primarily through three key areas of my life:

1) In 2004, my dad and I went on our first *Boys of Summer* documentary film journey, driving 20,000 miles in two months to see a game at each of the 30 Major League Baseball parks. We met all sorts of people with PD, care partners, advocates and medical professionals. We heard, were affected by, and shared lots of stories. We also saw self-protective silos in local support groups and agencies representing the PD community, which acted as miniature prisons, preventing collaboration and growth.

2) In 2014, about 13 years into his PD diagnosis, I saw my dad locking himself in a Parkinson's prison. His physical capabilities, especially golf, which were such a big part of his personality and identity, began to decline sharply. He began to see the losses in his energy and ability equating with a life he wasn't sure he wanted to live before he had even lived it.

3) Co-founding the nonprofit Parkinson's Place Las Vegas in 2017. At the time, Las Vegas lacked a cohesive support system for its growing PD community. Many in the Southern Nevada PD community felt locked out of getting what they needed. From this work, I was hired to be a clinical trial recruiter, working with a few UNLV professors in the PD community and collaborated with the Cleveland Clinic Lou Ruvo Center for Brain Health.

The Parkinson's prison extends beyond those that have it and their loved ones. It can manifest as a well-meaning practitioner unconsciously prescribing fear, anxiety and hopelessness under

the guise of “reality.” We must understand that if you’ve met one person with PD, you’ve met one person with PD. In other words, we can’t speak with absolute authority to anyone’s PD experience because we don’t know enough. I’ve heard hundreds of stories of doctors telling their patients with certainty what will happen. This needs to stop. We know PD is chronic, degenerative and there is currently no cure. People with PD need to be empowered to explore, discover and share their stories. Practitioners need to listen and learn, following Dr. Bas Bloem’s excellent prescription to humble themselves from God to Guide. The horrible irony is, even assuming best intentions, how antithetical those who act as Gods are to the Hippocratic Oath: “Do no harm.”

This is the razor’s edge: accepting the difficult truths of PD without becoming imprisoned by them. Many people with PD report hiding their symptoms so they don’t worry or frighten others or draw unwanted and perhaps embarrassing attention. This is stigma, defined as “a mark of disgrace associated with a particular circumstance, quality, or person.” When the person becomes defined by, rather than accepting of, PD they can become imprisoned in that belief system. There is hope. It starts with acceptance of being in a self-imposed prison. Before you say “not me” - consider the premise again: “denial is the greatest sickness facing our society today”. Yes, the frustrating realities of PD for everyone associated with it are real. However, they are only part of one’s life. The goal of living well with PD begins with accepting having it, rather than it having you. The acceptance of this power, in the form of regular daily choices, is the first step to breaking out of the Parkinson’s prison. A related experience to the Parkinson’s prison that may appear to be its opposite is the “Superhero Syndrome.” This is when the person with PD reports only the best of what’s going on in an effort, perhaps, to convince others that everything is “fine”. This is associated with not wanting to be a burden and the positive feedback one receives for appearing to be strong: “you’re so brave,” “you look great,” “you are my number one patient.” It’s not that any of these statements are inherently bad or wrong. They can, however, trap the person receiving them into thinking that’s how things, or they, should be all the time. The danger lies here in becoming performative for the positive feedback, masking rather than expressing, denying the whole truth - which includes the fact that PD is unpredictable, wide-reaching and generally sucks. But that’s PD. And a healthy relationship with it - meaning you having it rather than it having you - means it’s just a part of you that’s sucking, not all of you being sucked.

Beware, this path to the middle ground of acceptance and continuing curiosity is a long and arduous journey. It’s also dangerous - all meaningful journeys have high stakes, often life or death. The good news is we can choose to travel together, on the shoulders of (mostly) friendly giants to begin taking practical steps toward a better quality of life. With each step, we learn to let go of what is lost or has run its course and put our energy and focus into what is currently possible.

A recent study by Araceli Alonso-Canovas et al. points to personalized pathways of breaking out of the Parkinson’s prison. It began with a question from a person with PD, Jos Woeten, asking his doctor, Bas Bloem, if there was such a thing as a silver lining to having PD. The crucial and all too rare thing that happened next was that Dr. Bloem listened to and explored the inquiry. His

team posted a video on social media asking for people to share their feelings about a possible presence of a silver lining. They received 138 answers and 113 (82%) of them included positive experiences. They were mostly people with Parkinson's (85%), with the remaining being health care professionals (9%) and care partners (6%).

One of the key takeaways was the individuality of the responses - in other words, by engaging in the things they could have positive influence over, they felt empowered and happy. It's important to note the frustration of the 14% who reported their lives being worse since being diagnosed with PD. This is not in any way, shape, or form a call for anyone to simply "get over it" or pretend it's all good. It is, instead, a recognition of what is possible, that a silver lining may exist should the individual wish to seek it out; that a Parkinson's diagnosis need not be a death sentence or, perhaps worse, a life of imprisonment.

Click to pre-order your copy of
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This book will ship in late August 2024.