



## Fading

Nate Worrell

I sit on a swing and gently sway. The seat, once red as a barn, is now a pale pink strip of rubber, almost completely bleached by the sun. Any observer could label it as 'faded.' But at what point did it earn this superlative? It certainly didn't happen overnight. It wasn't sanguine one week and bloodless the next. And if you flip it over, its vibrant hue still radiates in defiance, a vestige of the swing it once was.

My father is fading. Parkinson's. A disease with a strong link to eventual dementia and mental issues. For now, he's vibrant. I look at him and most of the time, I see the guy who raised me. But when he is still, he is not *completely* still. His left hand has an unmistakable quivering. It is an outward manifestation of an internal declination.

So, I swing, contemplating mortality, replaying movies of childhood in my head. Maybe I can preserve his image against the forces that want to erase it. Maybe I can be the underside of the swing.

Today, my pop doesn't need assistance, perhaps in part to his active lifestyle. He had a full career in the Air Force as a nurse anesthetist and spent another decade as a civilian gas passer. For the past 25 years of his life, he's been an avid Alaskan: biking, hiking, skiing, and yanking hundreds of salmon torpedoes out of raging rapids.

He is officially retired this year, adjusting to a new life in a charming lakeside home in his birth state of Wisconsin. On our last call, he told me about how he's raking out the weeds in the pond so that his grandkids can have a pleasant swimming area.

Having purpose is certainly one of the things that gives my dad his color. What will happen if Parkinson's takes this away?

While the actual progression of the disease is varied, like other neurological and mental diseases of aging, it is commonly a gradual process. This glacial leeching of faculties is one sense a slow and cruel torture. On the other hand, it allows time for adjustment and preparation. There is going to be, hopefully, a long time before my dad will be a safety risk if left unsupervised. But, like taxes and dentist appointments, eventually we will have to deal with it.

For dad, life goes on. He is a *carpe diem* guy. His dad (miss you gramps) and two siblings faced "essential tremor", a different kind of neurological condition that involves shaky hands. The main difference is their tremors worsen when they try to do something, like eating soup, whereas dad's shakes happen at rest. Yet, none of them griped once about it in public, or let their conditions deter them from full and productive lives. Dad will keep going until he absolutely can't.

I swing back and forth, a human pendulum, and my thoughts go from dad to mom.

Mom is a different story. She doesn't have the diagnosis, but she is certainly affected by it. She keeps mental notes on how much more hunched his back has become every week, and in every conversation will make remarks about how much quieter his voice is getting. She is hyper aware of the fading.

She worries about how she's going to care for him. I don't know if she knows who she is without him. She distracts herself by picking cucumbers and tomatoes out of the garden. It brings her joy, but the threat of Parkinson's looms over her like a thunder cloud holding produce-shredding hail. She wanted to enjoy retirement, not worry about things that happen when you're "old".

They live in a rural town. It's the kind of place where you are on a first name basis with the Dave at the hardware store. The school playground probably has a wheel of death, and I imagine the swing set seats are white as bone. There isn't a senior care center. The nearest hospital is miles away. Their future caretakers will be their neighbors, their siblings, and me. The workforce will be paid in beer, cheese, and casserole.

Alternatively, maybe they will be able to get a mail order robot to help. Telemedicine, passive monitoring via 'smart' devices, A.I chatbots, and robotic companions are all part of a technology driven set of solutions in the aging space. However, you can't buy Nurse Bot 3000 with last winter's venison sausage and dad is not a fan of tech anyway.

Meanwhile, the costs continue to add up. Medicines may be required to help with the dopamine production. Therapists may need to be consulted to deal with the added stress, depression, and anxiety he or mom are dealing with. Home adaptations, transportation assistance, and other unplanned expenses are going to come out of their retirement bucket. It's a nest egg that my dad has worked hard to earn and maintain. Although don't get him started on his poor track record with financial institutions unless you really want to see him turn red.

I'm thankful that amidst a tough diagnosis, they're fortunate to have financial resources. For many of their neighbors and the larger aging population, this won't be the case.

Even with full mental acuity, it is difficult to navigate the labyrinth of support options. Furthermore, most of these solutions are designed to address a person once they have become faded, not while they are fading.

I've spent a good portion of my career in the actuarial playground of Long-Term Care Insurance. One potential benefit trigger is 'cognitive decline.' This is an umbrella term that largely covers Dementia and Alzheimer's. The exact qualifications may vary by product or company, but impairment generally needs to be severe. So, even if benefit payments would help, it is uncertain if and when they will arrive.

Public solutions are available but may have onerous qualification requirements as well as benefit limitations. States are working through changing income qualifications and expanding coverage situs options. Several are at the drawing board to define alternative policies to provide financial relief to seniors and their caregivers, but this too is a waiting game and will also add to the administrative and mental burden.

Further costs will have to be borne by other family members, and it could be a double whammy as they take time away for work to provide care.

I grip the chains on the swing a little tighter and lean back until I'm looking at the world upside down. It is amazing how much one word can change your life. One verdict from a doctor's office flips the script. The entire narrative pivots. Cognitive dissonance, mental inertia, sets in and you want to refuse the news. What do the doctors know anyway? But you cannot erase it. The world is different now.

We are all fated to be faded. We just don't know how it will happen or how long it will take. What will you do when you or someone you love gets their diagnosis? How will you respond? Do you have people around you to lean on for

support? Is there a pool of money to draw from? What else can you do today that will help you prepare for tomorrow?

For me, I'm happy to take a moment to enjoy the parabolic arc as I push off one more time and feel the rush of wind on my face, and I reflect on one of my dad's favorite quixotic phrases, "No matter where you go, there you are." It's an apt philosophy in the face of neurological disease. In part, it gives perspective. It reminds me that while we have a lot to worry about ahead of us, we can only visit the future in our minds. We have today and today may be as good as it's ever going to get. Additionally, the quaint quip advocates acceptance. We may long for the brightness of youth and dread the graying of old age, but life is indeed a journey and there will always be ups and downs. So why not try to embrace these precious moments we have, whatever they are, wherever they take us?

My father will fade, but not before I challenge him to a game of cribbage. First Jack deals.

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## POSTSCRIPT FACTS AND FIGURES

### FROM THE PARKINSON'S FOUNDATION

- Prevalence/Incidence: of Parkinson's is tricky. It is often undiagnosed for a long time. And there have been limited studies. "Prior to this 2018 study, the last major PD prevalence study was completed in 1978." Lastly, the data is messy. That said, the latest study suggests an uptick in incidence, possibly partially attributable to better diagnostics.
  - Proposed incidence rate for age 45+ is 62 per 100,000. Incidence increases with age.
  - Applied to population, this would be 90,000 new cases a year, up from 60,000.
  - 930,000 individuals are estimated to have Parkinson's as of 2020, and that number is estimated to increase by 2030 to 1,200,000.
- Burden of Disease:
  - Annual costs of PD in the US are currently estimated to be \$52 billion per year and are estimated to grow to \$80 billion.

REFERENCE: <https://www.nature.com/articles/s41531-022-00410-y>

### FROM OTHER SOURCES

- Rank among other Neurodegenerative Diseases: In the US, Alzheimer's dominates at over 6 million people. Parkinson's is a distant second, almost tied with Multiple Sclerosis at around 1 million each. ALS and Huntington's Disease complete the inventory. Globally, there are similar distributions.
- Rank Among Other Neurological Diseases: When looking at [a bigger spectrum of brain disease](#), **Stroke** jumps out as a dominant player, along with Traumatic Brain Injuries and Headache Related conditions affecting more people than *neurodegenerative disease*.

### SOA RESEARCH INSTITUTE RELATED RESEARCH

- Informal Caregiving: <https://www.soa.org/resources/research-reports/2023/informal-caregiving-reducing-burden>
- Long-Term Services and Supports Usage: <https://www.soa.org/resources/research-reports/2023/2023-long-term-services-support/>
- Late\_in\_Life Decisions Guide: <https://www.soa.org/resources/research-reports/2022/2022-lil-decisions-guide/>
- Neurology Deserts: <https://www.soa.org/resources/research-reports/2021/dementia-neurology-deserts/>
- Age Wise Infographics: <https://www.soa.org/research/age-wise/>
- Megatrends Affecting Retirement: <https://www.soa.org/49919d/globalassets/assets/files/resources/research-report/2023/2023-megatrends-impacting-retirement.pdf>