

Choosing to Live Well with Parkinson's Disease

Scott Rider and Jim Morgan



Who Are We

“Just two ordinary guys with Parkinson’s disease trying to make a difference.”

Scott Rider

62 years old

**Financial Planner,
Retired**

Diagnosed in
2006 at 47 years
old



Who Are We

“Just two ordinary guys with Parkinson’s disease trying to make a difference.”

Jim Morgan

63 years old

Attorney, retired
since October 31,
2021

Diagnosed in 2007
at 48
years old.



Our Goal Today

→ **Help and encourage you if you have PD like us.**

→ PD is NOT a death sentence. Rather, it IS an opportunity.

Living with PD is not easy.

There are some things beyond our control.

→ PD is a new way of life and we are in control of, at least, four specific factors.

Four Key Factors to Living Well with PD

Attitude

01

Strategy

02

Exercise

03

Involvement

04

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Attitude

PD is an opportunity

What it's really like

Everything is a bit off, not quite right



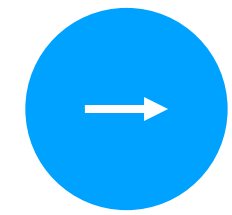
Attitude

→ Have you ever heard someone say, “I’m not going to be defined by _____”?

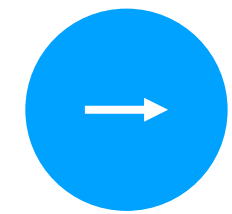
We’re talking about just the opposite

→ We decided early on that we are okay being known as “the guys with PD”

Our Goal Today



We each felt sad for a minute, but then we decided that we would embrace the challenge



We decided that our battles with PD could help others with PD and people in general

Everyone has challenges (e.g., financial, health, relationships)

We knew people would be watching how we handled our challenges with PD

Attitude



A little secret:

Helping others helps us too.
In fact, we probably benefit the most.



Head Games



Attitude

→ Head/Mind Games (AKA “cognitive restructuring”)

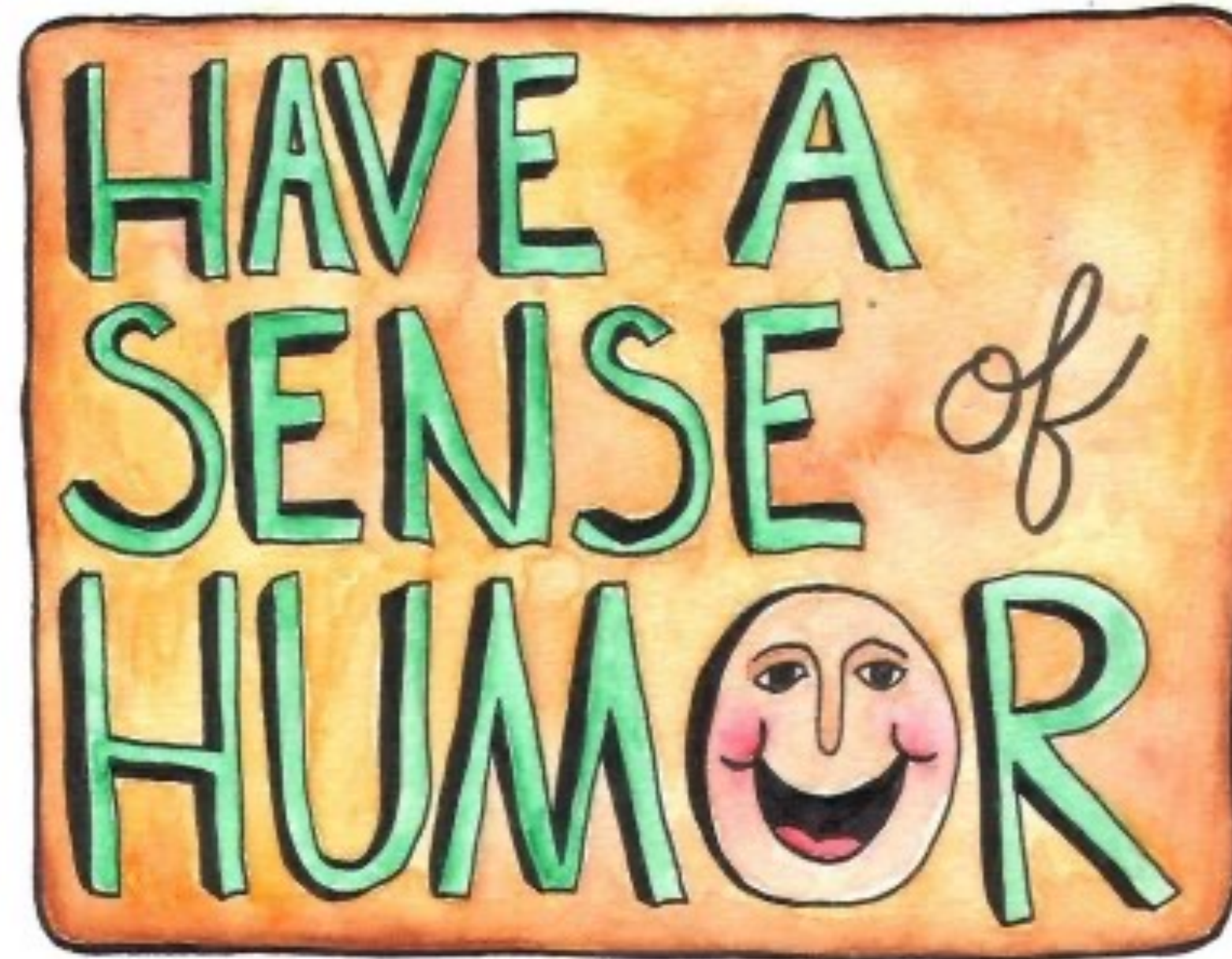
→ Scott’s family thinks he is the king of mind games, because:

He needs to reshape his daily thoughts because this is not the life he imagined

He can’t think too far in the future because he knows he’s not going to get better

It’s this moment, right now, that matters most

Attitude



Know a few jokes

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Strategy

→ Have your own strategy

→ People with PD tend to avoid social situations; they want to withdraw

Have a plan that you practice, even if just in your mind

#WEHAVEAPLAN



Strategy



Consider your care partner

They want to be with you in social situations

They are not embarrassed by you and love you



Strategy

- Seclusion is not good for any of us

Prove to yourself that you can adapt and adjust

-
- Others care about you and want to see you and know how you are doing

-
- You can demonstrate to them that you can live with PD



Strategy

- Have a pre-planned introduction
- If going to a social situation

Think about the type of glass you are going to hold

Eat before you go

Scout out the room for possible trip hazards and chairs

Use the bathroom before you go

Never hesitate to ask for help



Strategy

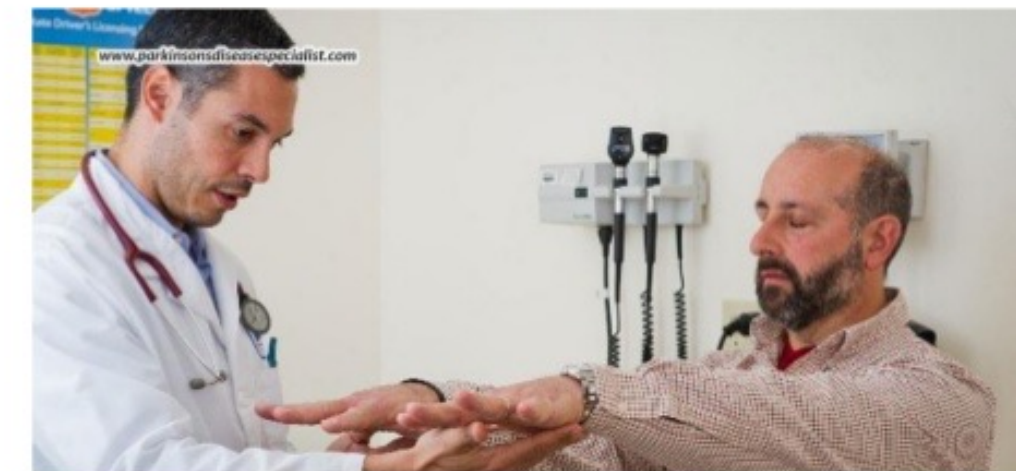
→ Strategize how to dress, eat and live

→ Consult a physician who is a movement disorder specialist (MDS)

Only 9% of PWP see a MDS

Why Is A Movement Disorder Specialist Beyond A General Neurologist? – Dr. Shivam Mittal

A movement disorder specialist is a neurologist; but a specialized one to treat severe movement disorders. While a general neurologist can treat patients with more than 100 neurological conditions, a movement disorder specialist can treat ailments like Parkinson's disease, dystonia, chorea, tics, tremors, Tourette's syndrome, and Huntington's disease. This is because they have received additional training in these disorders, and are on the cutting-edge of knowledge and treatment of these specialized ailments. Therefore, it is best to see such specialists when you are facing any movement disorders, as they are best equipped to tailor a plan of care for you and your specific needs. However, a professional [movement disorder specialist in Bangalore](#) like Dr. Shivam Om Mittal, works with a team of neurologists and therapists to provide a more holistic and complete level of care, and the highest possible quality of life to the patients.



Movement disorder specialists can be trained an additional year or two, specifically with patients suffering from Parkinson's disease and other movement issues. This is why their practices are focused specially on patients with such disorders. Moreover, they have access to various treatment options and specialty care, and opportunities for clinical trial participation that may not be available to general neurologists. Apart from medications,

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Exercise

Exercise is the most important RX

Total HealthWorks

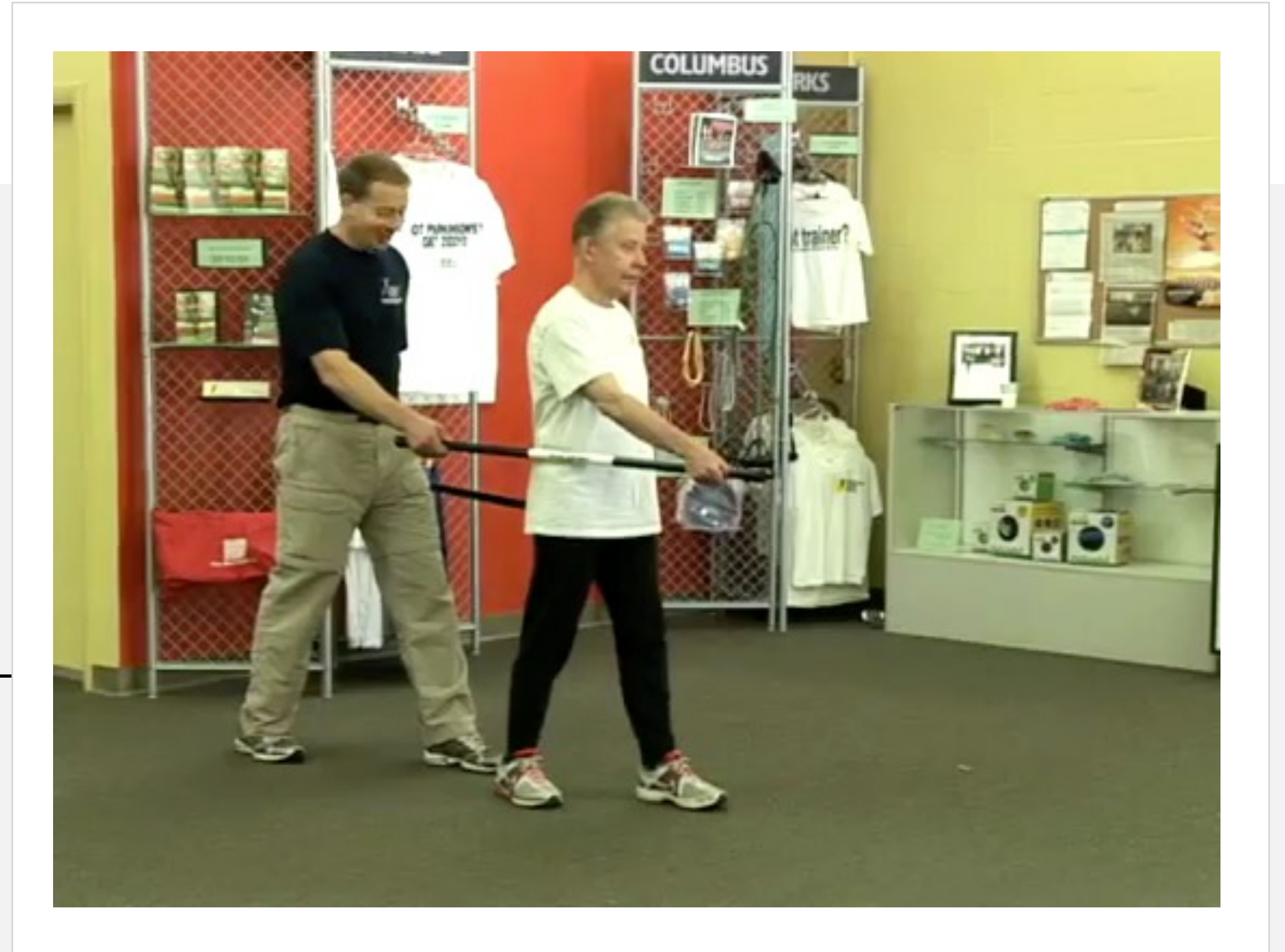
Personal trainer

TOTAL
HEALTHWORKS

Exercise



Ziddy Sticks



Exercise



Biking



Exercise

→ Rock Steady Boxing

60,000 Americans are diagnosed with PD annually

871 Rock Steady Boxing programs around the world

43,500 Parkinson's boxers training at affiliate programs worldwide



Exercise



Set an Exercise Goal

Exercise Daily

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Involvement

- Meet people who inspire you

- Living with PD is a way of life

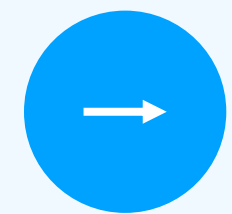
- Immerse yourself into the PD world

- Join a support group

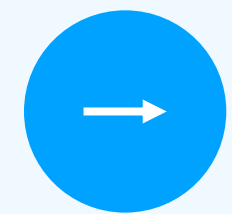
It is a place of encouragement

It is a place to gain knowledge

Involvement



Many great organizations doing incredible things in the Parkinson's community



We have chosen to join forces with the Parkinson's Foundation whose mission it is to make life better today for people living with Parkinson's



Strategy

Jim's Deep Brain Stimulation (DBS) Surgery

→ University of Miami — September 16th and 23rd, 2022

→ Boston Scientific Vercise DBS System (rechargeable)



Strategy

Jim's Deep Brain Stimulation (DBS) Surgery

- PD progress pretty slow for me in the early years
 - Switched to carbidopa/levodopa (Sinemet and Stalevo) to continue to be able to function at work, which caused increasingly more severe dyskinesia.
 - Not so much tremors but more rigidity (bradykenesia)
 - To counter the dyskinesia, I began taking amantadine, which cause incredible drowsiness (I woke up at a red light having bumped into the lady in front of me)
 - Tried all of the different meds with all of the ugly side effects (headaches, nausea, drowsiness, brain fog)
-

Strategy

Jim's Deep Brain Stimulation (DBS) Surgery

→ At the time of my surgery:

8 to 10 Sinemet pills a day

Highest dose of Neupro patch (24 hour timed release dopamine agonist)

Extended release carbidopa/levodopa at bedtime to alleviate severe dystonia in the morning

Extended release Amantadine (for dyskinesia)

Strategy

Jim's Deep Brain Stimulation (DBS) Surgery

→ Most bothersome symptoms:

Brain fog and drowsiness began to severely impact my ability to work.

Difficulty concentrating

On a few occasions, I fell asleep during conference calls (on one occasion (that I know of) it was mid-sentence and I was the one speaking)

DYSKINESIA

Strategy

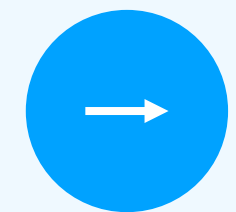
Jim's Deep Brain Stimulation (DBS) Surgery



Strategy

Jim's Deep Brain Stimulation (DBS) Surgery

Today:



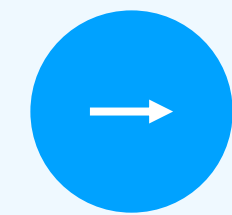
I have reduced my meds from the equivalent of 30 pills a day to a very low dose of Rytary four times a day.



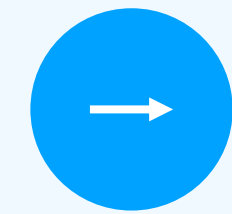
All brain fog and dyskinesia are essentially gone.

Strategy

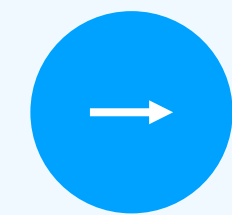
Jim's Deep Brain Stimulation (DBS) Surgery



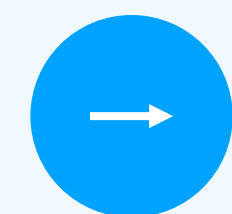
Everyone says, "I wish I did it sooner"



You have to be patient with the post-surgery programming



Your body needs to adjust to the new and different stimulation, while you understand what the stimulation is and is not doing



Be realistic in your expectations