



The Importance of Building Your Care Team

Jaime Hatcher - Martin, MD, PhD, FAAN
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Who am I?

- Movement Disorders Neurologist
- Director of Movement Disorders at Synapticure
- Researcher
- Telehealth Advocate



Dealing with the diagnosis of Parkinson's disease is hard enough. You should be able to rely on a team that hears and acknowledges your challenges while helping you navigate the care system.

You shouldn't have to always be your own quarterback.

Overview

- What is a Comprehensive Care Team?
- Why is it important?
- Who does it include?
- Where can you find one?
- Synapticure



What is a Comprehensive Care Team?

A group of healthcare professionals that works together to provide expert care and maximize your quality of life



Why is it important?



The nonmotor features of PD –including psychiatric disorders, cognitive decline, sleep disturbances and dysfunction of the autonomic system—are more predictive of perceived quality of life than motor symptoms.

Worse quality of life is associated with more frequent hospitalizations and significant care partner strain.

Who is on a Comprehensive Care Team?

- Neurologist, preferably including a Movement Disorders Specialist
- Primary care physician
- Therapists - physical, occupational, speech
- Exercise in training
- Dietician/nutritionist
- Psychiatrist, psychologist
- Neuropsychologist/Cognitive
- Genetic
- Case manager/coordinator
- Care navigator
- Neurosurgeon
- Other specialists
- Family and friends
- Other people with Parkinson's

How can I afford this?!

Why is a Movement Disorders Neurologist Important?

- Specialized training
- See movement disorders all day, every day
- Understand nuances of medications
 - how they work together (or against each other)
- Design a personalized plan
- Side effects versus symptoms
- What's NOT related to PD
- May be more up to date on clinical trials or even administering them



Primary Care Physician



- Helps coordinate your care
- Focus on immediate and long-term health needs
- Age-appropriate screenings
- Keeps you healthy beyond PD

Physical Therapy

- Help maintain/improve mobility
 - Walking
 - Balance
 - Strength
 - Posture
 - Flexibility
- Ideal to have someone trained in PD-specific therapies



<https://www.lsvtglobal.com/LSVTBIG>

Physical Therapy

Today, I walked. With a lot of help. I thought my days of walking were over, but they are far from over.

As my ALS progressed, I stopped going to PT because the travel was too much. When @synapticure and @getlunacare announced a partnership to bring PT to my home...

Occupational Therapy

- Fine motor skills, independence, activities of daily living
- Cognitive rehabilitation
- Alternative communications
- Home safety-evaluation and home modifications
- Ideal to have someone trained in PD specific therapies



<https://www.sralab.org/services/parkinsons-disease-movement-disorders-program>

Speech Therapy



<https://www.lsvtglobal.com/LSVTLOUD>

- Speech
 - Projection
 - Enunciation
- Swallowing - assessment, tips
 - Coughing, increased throat clearing
 - Aspiration pneumonia
 - Diet consistencies
- Communication
- Ideal to have someone trained in PD-specific therapies

Exercise Instructor/Personal Trainer

- May be beneficial for those not used to exercising
- Extend benefits from PT
- Key exercise elements for PD
 - Balance
 - Strength
 - Aerobic
- Maintain motivation
- Classes - boxing, dance, yoga, tai chi
- Understands safety issues in PD, safe instructor-to-participant ratio



<https://www.argusleader.com/story/news/2017/05/22/rock-steady-boxing-punching-out-parkinsons/332408001/>

Dietician/ Nutrition



- Healthy diet
- Weight maintenance/gain/loss
- Can help design a diet in accordance with your chewing and swallowing needs
- Discuss how certain foods and timing of them can affect medication effectiveness

Psychiatrist/ Psychologist

- Depression and anxiety are common
- Behavioral changes
- Can understand nuances of medications, what is safe to use in PD
- Familiar with chronic disease, geriatric (if relevant)
- Coping mechanisms



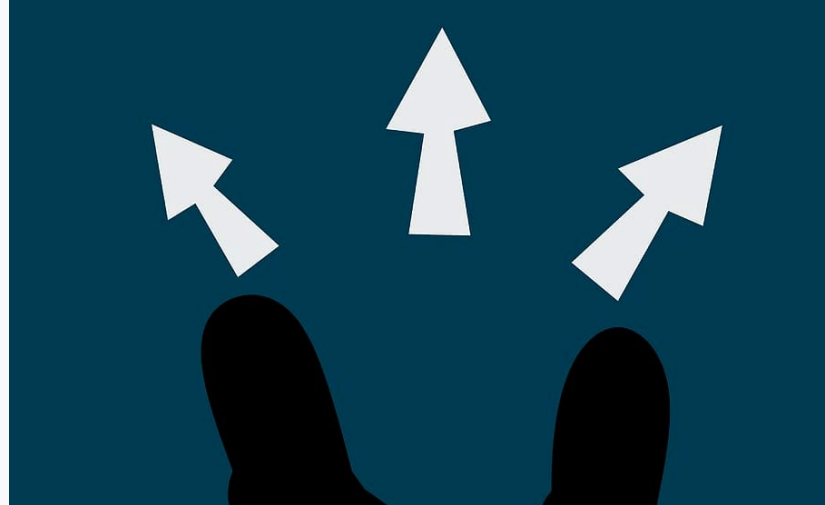
Neuropsychologist



- Intersection between neurological disease and behavior
- Cognitive and behavioral assessments
- Ideal to have a cognitive baseline
- Can tease apart expected cognitive changes in PD vs dementia vs depression vs meds, etc
- Identify strengths and weaknesses
- Develop interventional strategies

Social Worker/ Care Coordinator

- Create change, encourage resilience, coping mechanisms
- May be able to provide some counseling
- Help navigate the health system



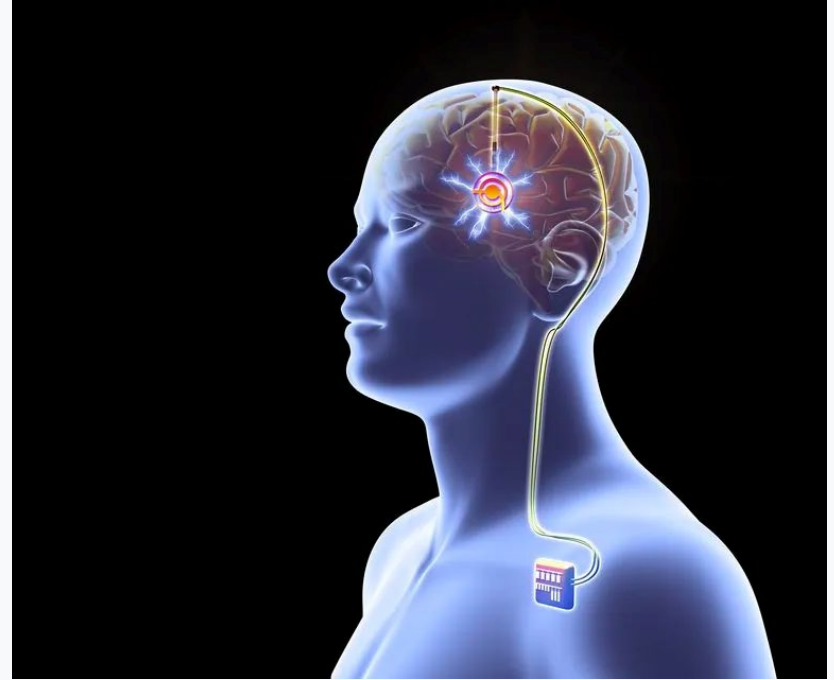
Genetic Counselor

- Discuss what genetic testing entails
- Understand what results could mean
 - Not just for you but your siblings, parents, children, etc
- Explain nuances of genetic results (not always yes/no)



Neurosurgeon

- Advanced surgical therapies
 - Deep Brain Stimulation (DBS)
 - Focused Ultrasound (FUS)
 - Lesioning
 - Some research studies
- Work closely with neurologist to identify ideal candidates



Other specialties

- ENT



- Gastroenterology



- Urology



- Dermatology



- Cardiology



Family & Friends

- Major role in care and well-being
- Emotional and physical support

Other people with Parkinson's

- No one else quite “gets” it
- NO need to explain
- Tips and tricks



Where can I find one?

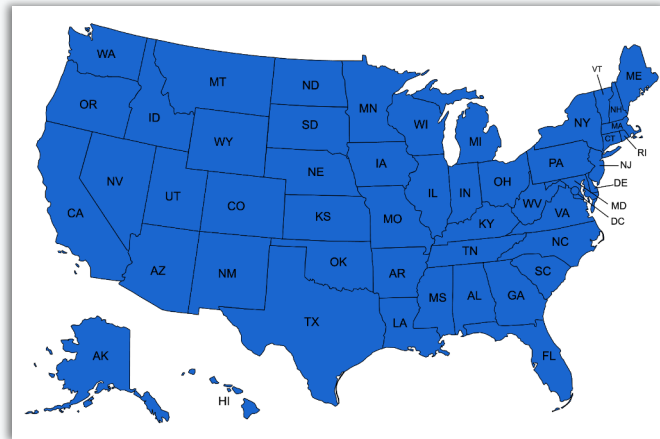
- Large academic centers and health systems may have one
 - Centers of Excellence, Comprehensive Care Centers, etc
- Piecemeal
 - PMD Alliance can help
- Synapticure



Daniel de la Hoz/iStock

Synapticure

- Fully virtual teleneurology service (i.e., care from the comfort of your home) for those living with diseases like PD and ALS
- Founded by a patient and his family
- Neurologists who wanted the ability to spend more time with each patient
- Work *with* your existing team to help fill in the gaps and provide you with the best, most up-to-date, evidence-based care



“I can't explain how much I love Synapticure as a whole. Everything from the doctors to the care team is **beyond what I expected** .”

Synapticure

- ✓ Expert neurologic care with frequent visits available
- ✓ Collaborative medication review, education
- ✓ Care coordination to help arrange local ancillary services (virtual or in-person)
- ✓ Determining clinical trial eligibility
- ✓ Insurance navigation and medication approvals
- ✓ Genetic Testing
- ✓ Insurance-based



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AS SEEN IN

CBS

The New York Times

WGN

POLITICO

People

Synapticure

Recap

- Collaborative-team approach is best
- Maximize quality of life
- May take time to build your team
- Needs may change over time
- May not need all of these
- There are *many* resources available





Thank you!!



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