

# How to Advocate for yourself





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# Cornerstones to Living Well with Parkinson's

Knowledge
Community
Medical Team
Exercise & Nutrition
Attitude



#### **Medical Team**

Multi-Discipline Approach

- Movement Disorder Specialist
- Neurologist
- Physical Therapy
- Speech Therapy
- Exercise Therapist
- Occupational Therapy
- Nutrition/Diet
- Gastroenterology
- Etc....





# **Knowledge = Be Informed + Be Connected**

- Davis Phinney Foundation <a href="https://www.dpf.org">www.dpf.org</a>
- Michael J. Fox Foundation <u>www.michaeljfox.org</u>
- World Parkinson's Congress <u>www.worldpdcoalition.org</u>
- ParkinsonsDisease.net <u>www.parkinsonsdisease.net</u>
- Parkinson's Foundation www.parkinson.org
- Local Parkinson's Support Groups
- When Life gives you Parkinson's Podcast
- Local presentations, symposiums, and conferences



# Community - Support Ecosystem

- Care Partner/Care Giver
- Family
- Friends
- Support Groups
- Outreach to others



How can you help? Pay it forward!



- Numerous Parkinson's Unity Walks in New York City
- The Udall Center of Excellence for Parkinson's research at Pennsylvania Hospital
- Various volunteer roles with the Davis Phinney Foundation
- Numerous cycling events in Colorado to raise money for the Davis Phinney Foundation
- Organize a local cycling to raise money awareness for Parkinson's
- Guest speakers at Parkinson's conferences and support group meetings
- World Parkinson's Conference in 2016 and 2019, Portland OR and Kyoto, Japan
- Panelist at MJ Fox conferences
- Parkinson's policy forum in Washington DC







### Caregiver Advocacy

# Self Advocacy

- Take time to do activities that you enjoy. Take time for yourself. Take time to be with friends.
- Get good sleep, eat well and exercise
- Reduce stress / ask for help / accept limits
- Give yourself time to adjust you will find your stride



# Caregiver Advocacy

# **Community Advocacy**

- Be well informed using reliable resources
- Attend conferences and support groups, participate in zoom discussion, listen to presentations / podcasts, read
- Give others personal support
- Be active share what you can!



# BE INFORMED. BE ENGAGED BE CONNECTED. BE COURAGEOUS. BE ACTIVE.

https://www.worldpdcoalition.org/