

Parkinsons Disease: Preliminary Guide to Information

Compiled by Gail Bardhan, 2019

Disclaimer: This guide has been compiled by a caregiver, and individuals with Parkinson's. It is based on Internet research, and questions pertaining to advice, information etc. should be directed to medical professionals. Each website contains several sections and numerous subsections, with various types of information. This is meant to be an introductory guide to information. Many communities do have support groups for patients and their caregivers, including the Southern Tier of New York; the group currently meets at the Big Flats Community Center once a month.

For the newly diagnosed:

[file:///C:/Users/gail/AppData/Local/Packages/microsoft.windowscommunicationsapps_8wekyb3d8bbwe/LocalState/Files/S0/8133/Attachments/newlydiagnosedfl-GSF2\[9644\].pdf](file:///C:/Users/gail/AppData/Local/Packages/microsoft.windowscommunicationsapps_8wekyb3d8bbwe/LocalState/Files/S0/8133/Attachments/newlydiagnosedfl-GSF2[9644].pdf)

Organizations

American Parkinson Disease Association

135 Parkinson Avenue
Staten Island, NY 10305
1-800-223-2732
<apda@apdaparkinson.org>

Founded in 1961, APDA invests in program to provide patient services and educational programs. Their website sections include education, support, research, APDA in your community, as well as webinars, links to media coverage, and recent news. This group has a lot of website information for newly diagnosed and supports local support groups.

Free Handbook on Parkinson's Disease from APDA:

<https://www.apdaparkinson.org/handbook-download/>

Davis Phinney Foundation for Parkinson's

357 McCaslin Blvd
Suite 105
Louisville, CO 80027
<https://www.davisphinneyfoundation.org/>

“The Davis Phinney Foundation is a non-profit with a mission to help people with Parkinson's live well with the disease. It was founded in 2004 by Davis Phinney, the former professional road bicycle racer and Olympic medal winner. Phinney was diagnosed with young-onset Parkinson's disease in 2000 at the age of 40. Today, Davis is an inspirational figure in the cycling community and people living with Parkinson's.”

Their website includes:

<https://www.davisphinneyfoundation.org/resources/worksheets-and-downloads/>

Wellness and lifestyle self-assessments
Symptoms checklist
Medical information snapshots
Glossary

Michael J. Fox Foundation

<https://www.michaeljfox.org/>

Founded by actor Michael J. Fox, with the purpose of contributing to the elimination of Parkinson's through research to find a cure and information. Also hosts educational webinars and educational material. Has a listing of available clinical trials.

Website topics

-- Why we exist;

-- Understanding Parkinson's

Includes a 52 page book, Navigating Parkinson's (Parkinson's 360 degrees) which can be downloaded <https://www.michaeljfox.org/parkinsons-101>

- Guide for the Newly Diagnosed, Carey Christensen, et al, [https://files.michaeljfox.org/Guide for the Newly Diagnosed.pdf](https://files.michaeljfox.org/Guide%20for%20the%20Newly%20Diagnosed.pdf)

-- For Researchers;

--Take Action. .

There is also a section in Education and Inspiration, of books and resources, including other organizations in this guide; and a link to podcasts and webinars, etc. For example, the section "Ask the MD" provides access to various topics, such as physical therapy

Interested people may access their website, and choose various topics about which will be sent periodic emails: Research News; Foundation news and community events; Policy updates and action; Monthly E-Newsletter

National Institute on Aging

<https://www.nia.nih.gov/health/parkinsons-disease>

National Institute of Neurological Disorders and Stroke

1-800-352-9424 (toll-free)

braininfo@ninds.nih.gov

www.ninds.nih.gov

[*National Parkinson Foundation*] see: **Parkinson's Foundation**

Parkinson & Movement Disorder Alliance
(PMD Alliance).

Their mission is to provide opportunities for people with movement disorders to live better, learn and network with similarly afflicted people.

website subdivisions

- workshops and events
- online programs
- people with movement disorders
- care partners
- family members
- news

- care partners and family
- symptoms and treatments
- partnerships
- research
- wellness

resources

- support groups
- exercise and wellness
- medication assistance
- movement disorder specialists
- national, regional, and local organizations
- surgical treatment options
- certified PD care facilities

<https://www.pmdalliance.org/>

Parkinson's Disease Foundation SEE: **Parkinson's Foundation**

Parkinson's Foundation

200 SE First St., Suite 800
Miami, FL 33131
1359 Broadway, Suite 1509
New York, NY 10018
<https://www.parkinson.org>
(800-473-4636)

“In 2016, the National Parkinson Foundation merged with the Parkinson's Disease Foundation to form the Parkinson's Foundation. Today, with offices in New York City and Miami, the Parkinson's Foundation works towards making life better for people with Parkinson's disease by improving care and advancing research toward a cure.” They have lots of patient literature and programs. They are involved with advocacy and they have a Q&A board staffed by doctors and a support group forum.

This group sponsors Moving Day, held in various cities. See below: Parkinson's Foundation Greater Rochester. They are one of the largest groups for Parkinson's support and education. The University of Rochester Neurology affiliates with the Parkinson's Foundation.

Website sections, *with some additional subdivisions*:

--Understanding

<https://www.parkinson.org/understanding-parkinsons/10-early-warning-signs>

--Living with Parkinson's (includes a PD library)

--Managing Parkinson's

--In your area

For a list of professional medical providers within 100 miles of Corning NY:

<https://www.parkinson.org/Living-with-Parkinsons/in-your-area?zipcode=14830&NoBots=uDZR%2BtigGw59kE3kCaMHmBTgoFt80qd%2FCxxCVfeJf94%3D%7C4edcf547f8fb6d0b5d2c798b0429701e>

--Resources and support

--Helpline

--Patient Safety Kit (Parkinson.org/AwareInCare)

--Expert Briefings Webinar (or Parkinson.org/ExpertBriefings)

--Podcast

--.... Parkinson's Wellness Institute

--Ask the Doctor Form

--Order Publications

(Includes a free newsletter, which can be read online or received by mail)

--PD Library (OR: Parkinson.org/Library)

--New to Parkinson's

--Legal, Financial and Insurance Matters

--My PD Story

--Blog (Parkinson.org/Blog; the latest published PD research studies)

--For Caregivers

--Expert care

--Research.

Helpline is also available by phone, 1-800-473-4636; helpline@Parkinson.org

They can provide a specialist to answer PD questions; offer current information; referrals to health professionals and community resources; hour M-F, 9am-8pm EDT

Resource Finder: Parkinson.org/Keys

In the PD library section, in the Books subdivision, there is a book on Medications, which can be downloaded from the site, or purchased from the Foundation, by clicking on "Store". There was a previous edition, with a publication date of 2016.

Additional publications can be found at

https://secure3.convio.net/prkorg/site/Ecommerce?store_id=4003&PAGENUM=1

Facebook.com/parkinsonsondotorg

Includes a posting of the latest PD articles about research and managing the disease, along with links to free resources.

Parkinson.org/Podcast

Currently 55+ episodes and 100,000 downloads about the latest in PD research, medications, exercise and treatments. Subscribe through iTunes, Google Play and Tunein.

Parkinson's Foundation Greater Rochester

"The Parkinson's Foundation Greater Rochester Chapter is dedicated to making life better for people with Parkinson's disease by improving care and advancing research toward a cure. We provide a variety of support groups, education programs and respite grants throughout the greater Rochester area. Whether you are newly diagnosed with PD or have been managing it for years, a caregiver, family member or friend of someone with PD, we are here to help you.

https://www.parkinson.org/greaterrochester?gclid=EAlalQobChMlocirj-iQ4wIVQb7ACh22mQg8EAAYASAAEqJLFPD_BwE

Parkinson's Research Foundation

The Parkinson Research Foundation (PRF) is a federally recognized 501(c)(3) nonprofit organization that funds Parkinson research, education, advocacy and free services living with Parkinson disease. All contributions are tax-deductible to the extent permitted by law.

Funds Research

Publishes Scientific Findings

Advocates for Scientific Research and the Rights of People with Parkinson's

Promotes Parkinson Awareness by means of Local and National Outreach and Special Events

Funds Educational Conferences

Provides Funding for PARKINSON PLACE, a 9,000 square foot Multidisciplinary Care Center site in Sarasota, Florida offering over 50 FREE education and participation programs a month as well as ongoing video classes on www.ParkinsonPlace.org for the homebound and those outside the service area.

Website includes

---Latest News: stories relating to Parkinson's from the Internet. One can also subscribe to the PRF Newsletter

--Ask a Doctor: submitted questions with answers, plus the opportunity to post questions not previously answered

<https://parkinsonhope.org/>

UF Center for Movement

Disorders & Neurorestoration

3450 Hull Road Gainesville FL 32607

<https://movementdisorders.ufhealth.org/2013/07/28/helpful-tips-for-parkinsons-disease-hallucinations/>

Other online resources

<https://gsfriedman.com/wp-content/uploads/2019/07/Parkinsonandtechnology.pdf>

"Using Technology in Your Battle With Parkinson's", GS Friedman, October 2015 presentation

Gloria Friedman's website and blog:

<https://gsfriedman.com/2019/06/wpc2019-d/>

Cleveland Clinic

<https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview/management-and-treatment>

Mayo Clinic

<https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/symptoms-causes/syc-20376055>

American Association of Neurological Surgeons

<https://www.aans.org/en/Patients/Neurosurgical-Conditions-and-Treatments/Parkinsons-Disease>

<https://parkinsonsnewstoday.com/>

Compiled by BioNews Services, LLC; Their disclaimer: Parkinson's News Today is strictly a news and information website about the disease. It does not provide medical advice, diagnosis or treatment....

<https://www.webmd.com/parkinsons-disease/default.htm>

Various Articles on Parkinson's Disease

<https://curiouscast.ca/podcast/160/when-life-gives-you-parkinsons/>

"When Life Gives You Parkinson's" : Larry Gifford has developed an excellent podcast about Living with Parkinson's. He did a special series for the 2019 World Parkinson Conference. He adds a new episode weekly.

https://en.wikipedia.org/wiki/Parkinson%27s_disease

Brief listing of **websites for specific topics**

Apathy:

<https://www.parkinson.org/Understanding-Parkinsons/Symptoms/Non-Movement-Symptoms-Apathy>

<https://medium.com/parkinsons-uk/how-do-you-solve-a-problem-like-apathy-b5c87381b616>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3263557/>

(scholarly article on Apathy and Anhedonia *from National Center for Biotechnology Information*)

<https://www.verywellhealth.com/apathy-and-parkinsons-disease-2612192>

(a good article with practical tips for combatting apathy)

Depression:

<https://www.apdaparkinson.org/what-is-parkinsons/symptoms/depression/>

<https://www.healthline.com/health/parkinsons-and-depression#causes>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4878671/>

Scholarly article on Current Knowledge *from National Center for Biotechnology Information*

<https://www.michaeljfox.org/news/depression-anxiety>

(good information with links recruiting for studies)

<https://d2icp22po6iej.cloudfront.net/wp-content/uploads/2017/02/APDA1709-Supplement-Depression-D4V1.pdf>

(a printable PDF file on Depression and Parkinson's from APDA)

Exercise

Exercise in various ways is recommended: boxing, LSVT, tai chi, yoga, dance, etc.

[https://www.parkinsons.va.gov/NorthWest/Documents/Pt ed handouts/Exercise for PD 1-20-12.pdf](https://www.parkinsons.va.gov/NorthWest/Documents/Pt%20ed%20handouts/Exercise%20for%20PD%201-20-12.pdf)

There numerous exercises, such as LSVT, for which PD patients should seek guidance from physical therapists. There are two types – LSVT Loud, for improvement in speech, and LSVT Big, for effectively trains improved movements for any activity, whether “small motor” tasks like buttoning a shirt or “large motor” tasks like getting up from sofa or chair or maintaining balance while walking

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

<https://www.burke.org/blog/2015/6/what-is-lsvt-and-how-does-it-help-parkinson-s-disease/43>

There are YouTube videos, such as the following

<https://www.youtube.com/watch?v=fpTqcWs2NUY>

There are DVDs also available for purchase:

This is a brief list

Delay the Disease: Functional Fitness for Parkinson's Disease (David Zid)

Parkinson's Rise and Shine Morning Blast

Nutrition

https://parkinson.org/sites/default/files/attachments/Nutrition.pdf?_ga=2.5078387.1500681636.1560968308-1938236368.1538762824

Pain

<https://parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Advice-for-the-Newly-Diagnosed/Does-Parkinsons-Hurt>

<https://www.apdaparkinson.org/article/is-pain-a-symptom-of-parkinsons-disease/>

<https://www.michaeljfox.org/news/ask-md-pain-and-parkinsons-disease>

<https://www.verywellhealth.com/otc-pain-remedies-parkinsons-2612046>

Sleep disorders:

<https://www.apdaparkinson.org/what-is-parkinsons/symptoms/sleep-problems/> (this one includes a good 45-minute webinar)

<https://www.sleepfoundation.org/articles/parkinsons-disease-and-sleep>

Twin Tiers Parkinson's Group Facebook page:

https://www.facebook.com/search/top/?q=twin%20tiers%20parkinson%20group&epa=SEARCH_BOX

Parkinson's Road

<https://www.facebook.com/groups/2058779281064979/>

Exercises for Parkinson's

Rock Steady Boxing Program <https://rocksteadyboxing.org/>

“Rock Steady Boxing, a 501 (c)(3) nonprofit organization, gives people with Parkinson's disease hope by improving their quality of life through a non-contact boxing based fitness curriculum. In our gym, exercises are largely adapted from boxing drills. Boxers condition for optimal agility, speed, muscular endurance, accuracy, hand-eye coordination, footwork and overall strength to defend against and overcome opponents. At RSB, Parkinson's disease is the opponent....”

Website subsections:

--About

--Boxing Classes

--Blog & RSB News

--Shop

--Contact

LSVT

For exercises, such as LSVT, PD patients should seek guidance from physical therapists. There are two types – LSVT Loud, for improvement in speech, and LSVT Big, for effectively trains improved movements for any activity, whether “small motor” tasks like buttoning a shirt or “large motor” tasks like getting up from sofa or chair or maintaining balance while walking

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

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

<https://www.burke.org/blog/2015/6/what-is-lsvt-and-how-does-it-help-parkinson-s-disease/43>

There are YouTube videos, such as the following

<https://www.youtube.com/watch?v=fpTqcWs2NUY>

There are DVDs also available for purchase; here is a brief list of titles on Amazon:

LSVT Big: Homework helper! Volume 1.

•
Delay the Disease: Functional Fitness for Parkinson's Disease (David Zid)

Parkinson's Rise and Shine Morning Blast

Publications (internet and print)

<https://www.apdaparkinson.org/handbook-download/>

Free Parkinson's Disease Handbook:

A brief list of recently published books available through Amazon:

Friedman, Joseph. Making the connection between brain and behavior-coping with Parkinson's disease. 2013.

Hague, Tim. Perseverance: The Seven Skills You Need to Survive, Thrive, and Accomplish More Than You Ever Imagined. Viking, 2018

Written by a person with Parkinson's who won The Amazing Race Canada.

Le Verrier, Renee. Yoga for movement disorders: rebuilding, strength, balance... 2012

Lianna Marie. Everything You Need to Know About Caregiving for Parkinson's Disease. 2016.

Schechter, Steven H. Understanding Parkinson's disease: a self help guide. 3rd ed.

Schwarz, Shelley Peterman. 300 tips for making life easier. 2nd ed. Demos, 2006.

Toth, M. A. Puzzles for Parkinson's Patients: Regain Reading, Writing, Math & Logic Skills to Live a More Fulfilling Life. 2017

Vine, John. A Parkinson's Primer: An Indispensable Guide to Parkinson's Disease for Patients and Their Families. 2017.

Weimar, William J. Parkinson's disease: a complete guide for patients and families. 2013.

Zid, David. Delay the Disease-Exercise and Parkinson's Disease. 2nd Edition. 2017.

See the Parkinson's Foundation website (above) for additional titles, that can be ordered from the Foundation.