

Parkinson's Disease

What do I do Now?

A Guide for People with Parkinson's Disease & Their Caregivers

Written by
People in Connecticut Living with Parkinson's



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This Guide is dedicated to Connecticut's People with Parkinson's and their caregivers in the hope that it helps light the way on their journey of joy and challenges as they strive mightily to live as well as they possibly can. Because we ourselves are on the same journey, we remember how comforting and meaningful it is to know that we are not alone.

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We have tried to make this Guide's first edition as complete and as comprehensive as possible, acknowledging full well that there may be other sources and resources in Connecticut that are not yet included. Any such oversights or omissions are certainly not intentional, and can be addressed in future editions. We count on our readers to assist us in adjusting and updating this Guide for the continuing benefit of all those it may serve.

Please email any suggestions, additions and/or corrections to:
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A. WHAT IS PARKINSON'S?

Parkinson's disease (PD) is a neurodegenerative disorder that affects predominantly dopamine-producing ("dopaminergic") neurons in a specific area of the brain called substantia nigra. Symptoms generally develop slowly over years. The progression of symptoms is often a bit different from one person to another due to the diversity of the disease. Among the symptoms People with Parkinson's may experience are:

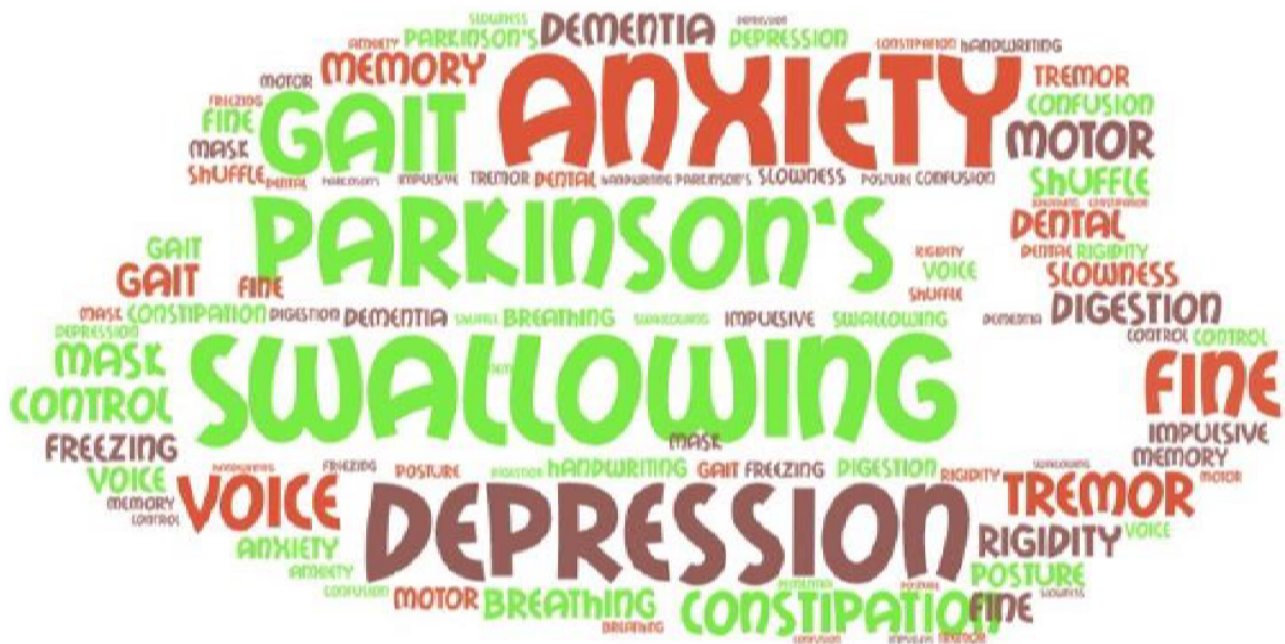
- Tremor - occurring mainly at rest and described as 'pill rolling' tremor in hands. Other forms of tremor are possible
- Bradykinesia - slowness of movement, one of the cardinal manifestations of PD
- Limb rigidity – a feeling of stiffness, difficulty putting on coats, robot like walk
- Gait and balance problems – walking in an awkward manner etc.
- Cognitive Impairment - disturbance of memory, thinking and/or language abilities

The cause remains largely unknown. Although there is no cure, treatment options vary and include medications and surgery. While Parkinson's itself is not fatal, disease complications can be serious. The Centers for Disease Control and Prevention (CDC) rated complications from PD as the 14th cause of death in the United States.

The first step to living well with Parkinson's disease is to understand the disease and its progression. It is possible to have a good to great quality of life with PD. Working with your doctor and following recommended therapies are essential in successfully treating symptoms by using an array of exercise, naturopathic programs and dopaminergic medications.

It is important to understand that people with PD first start experiencing symptoms later in the course of the disease because a significant amount of the substantia nigra neurons have already been lost or impaired. Lewy bodies (accumulation of abnormal alpha-synuclein) are found in substantia nigra neurons of PD patients. Scientists are exploring ways to identify biomarkers for PD that can lead to earlier diagnosis and more tailored treatments to slow down the disease process. Currently, all therapies used for PD improve symptoms without slowing or halting the disease progression.

In addition to movement-related (“motor”) symptoms, Parkinson’s symptoms may be unrelated to movement (“non-motor”). People with PD are often more impacted by their non-motor symptoms than motor symptoms. Examples of non-motor symptoms include: apathy, depression, constipation, sleep behavior disorders, loss of sense of smell, and cognitive impairment. See illustration below for more symptoms of PD.



Facts about Parkinson's

Parkinson's Disease affects one in 100 people over age 60. In Connecticut, there are approximately 10,000 people with the disease.

1/₁₀₀
OVER 60

10,000
in CT

Today, an estimated one million people in the United States and more than five million worldwide are living with Parkinson's Disease.

1M/US

5M/WORLD

Parkinson's Disease is caused by the death of dopamine cells.

60 to 80%

Of these cells are already lost by the time the motor symptoms appear.

Lesser-Known

Symptoms of Parkinson's include depression, apathy, fatigue, and dementia.

3 out of 5 Americans will suffer from a nervous system disease such as Parkinson's or Alzheimer's.

The exact cause of Parkinson's Disease is **UNKNOWN**

But both genetics and environment are causes.

Today's Best Parkinson's drug was **DISCOVERED** in **1967** and nothing equal or better since

Dyskinesia is often mistaken for a symptom of Parkinson's Disease, but it is actually a side effect of the PD treatment. Many patients report that dyskinesia to be as **debilitating** as the disease itself.

THERE IS NO CURE FOR PARKINSON'S DISEASE

Although there is no cure for Parkinson's yet, there are myriad ways to live a better life with the disease. This guide will give you and your family many different options and ideas for healthy living. It is then your choice to make a plan that fits your personal lifestyle and needs.

B. NEUROLOGISTS/MOVEMENT DISORDER SPECIALISTS IN CT

Neurology is the medical field to which people who begin to experience Parkinson's-like symptoms are referred. Many people with Parkinson's and their caregivers believe that neurologists who specialize in treating patients with Movement Disorders are particularly focused on the nature and needs of those with the Parkinson's diagnosis.

C. WHAT SHOULD I DO NOW?

1. *EXERCISE EXERCISE EXERCISE!*

a. Beat PD Today:

www.beatpdtoday.com, 860-463-3747

b. Delay the Disease:

Westbrook Valley Shore YMCA

<http://vsymca.org/delay-the-disease/>

c. Rock Steady:

Deep River – www.squaredcircle.com

East Hartford – www.barebonesboxing.com

d. Joint Effort: Low Impact Guided Exercise: Guilford, Old Saybrook, Branford jointeffortexercise@gmail.com, 203-458-668

e. General Parkinson's Exercise:

Danbury Medical Fitness center, 203-748-2551 x 364

West Hartford area, 860-787-5009

f. Therapeutic Exercise for PD/Get Tough Exercise Program

Middletown Senior Center, 860-798-5867

g. Tai Chi

Contact your local Senior Center and/or YMCA

Tai Chi for Better Balance; Village at South Farms, Middletown

Contact: 860-712-0823, tcush@snet.net

h. Bicycling

Pedaling for Parkinson's- Soundview YMCA Branford CT, 203-481-9622

i. Dancing with Parkinson's

Dancing for Joy: Branford, Middletown, and New Haven

Contact: Laura Richling, 203-624-5189 or 203-675-2930

Parkinson's Dance Class: Shoreline/Guilford and Old Saybrook

Contact Rose Costanzo, 203-458-4351

j. Yoga Contact your local Senior Center and/or YMCA and look in Park & Recreation activities in your local area

2. **Voice Therapy** for People with PD

www.lsvtglobal.com, 888-438-5788

LSVTLOUD, www.lsvtglobal.com

Rehab Concepts Guilford, 203-458-6268

New Britain Hospital for Special Care, 860-827-1958

Masonicare Wallingford, 203-679-6909

3. **Meditation**

4. **Mindful Movement**

5. **Massage**

6. **Senior Centers by Town In CT**

<https://chcact.org/wp-content/uploads/2013/04/ctseniorcentersbytown.pdf>

D. PARKINSON'S SUPPORT GROUPS – CONNECTICUT

Support groups provide a powerful network for information, socialization and collegiality for PWP's and their caregivers.

- CAP – Connecticut Advocates for Parkinson's
www.parkinsonsct.org, 860-266-6040

Branford chapter – Meets the 1st Saturday at 1pm
Branford Fire Headquarters
45 North Main Street, Branford, CT
allyson@parkinsonsct.org

Glastonbury chapter – Meets 1st Saturday at 11am
Wethersfield Police Station
250 Silas Deane Hwy
Wethersfield, CT
michelle@parkinsonsct.org

Southbury chapter – Meets 2nd Saturday at 10:30 am
Southbury Library
100 Poverty Road, Southbury, CT
Steve@parkinsonsct.org

- CPWG - Connecticut Parkinson's Working Group – CPWG.org
Meets 3rd Saturday at 10am
The Village at South Farms
645 Saybrook Road, Middletown, CT
Call: 860-704-9519

- CT APDA Affiliated Support Groups – CTAPDA.org –

The APDA offers support groups in many areas of Connecticut. For a complete listing, please go to www.ctapda.org or contact their Information & Referral Center at (860) 490-5384. As of this writing, the CT APDA offers support groups in Avon, Bridgeport, Darien, East Windsor, Ellington, Enfield, Fairfield County, Glastonbury, Guilford, Hebron, Milford, Mystic, New Britain, New Haven, Ridgefield, Shelton, Southbury, South Windsor, Trumbull, Wallingford, Waterbury, West Hartford, Westport, and Willimantic.

- Torrington Area Parkinson's Support Group - TAPSG

www.torringtonparkinsonssupportgroup.com

Contact: Susan Pelchat, sgpelchat@sbcglobal.net

860-489-1677

- Contact your local senior center

E. CAREGIVER RESOURCES

There is no overstating the integral role of caregivers in loving, supporting and encouraging those in their care. Much helpful information about caregiving is available within the websites listed in Section F of this Guide: "Organizations that Support PD Patients and Families". No matter the source, there is uniform agreement on several undeniable truths: Caregiving is hard work; Caregivers need to remember to take time and make time for themselves; and Caregivers should ask for help when they feel frustrated, exhausted or overwhelmed. In other words, caregivers sometimes need care too.

F. ORGANIZATIONS THAT SUPPORT PD PATIENTS AND FAMILIES

- American Parkinson Disease Association (APDA)
adpa@adpaparkinson.org, 1-800-223-2732
- Connecticut Advocates for Parkinson's (CAP)
Parkinsonsct.org, 860-266-6040
- European Parkinson's Disease Association, info@epda.eu.com
- Michael J Fox Foundation Michaeljfox.org, 1-800-708-7664
Fox Trial Finder foxtrialfinder.michaeljfox.org
- Parkinson's Foundation Parkinson.org, 1-800-473-4636
FREE EDUCATIONAL MATERIAL!
- The Davis Phinney Foundation contact@dpf.org, 1-866-358-0285
FREE EDUCATIONAL MATERIAL!

- The Parkinson Alliance contact@parkinsonalliance.org, 1-800-579-8440
- Parkinson's Action Network (PAN)
Parkinsonaction.org, 1-800-850-4726

G. ADDITIONAL RESOURCES

- **BLOGS/VLOGS:** We encourage readers to access the internet for myriad opportunities to learn about and learn from the personal stories about living well with Parkinson's that are available. Use Google or other such search engines to access "blogs for Parkinson's" or go to Youtube/Video Tube to access "vlogs for Parkinson's".
- **Connecticut Medical Marijuana Program**
dcp.mmp@ct.gov, 860-713-6066
Or Search "Connecticut Marijuana Doctors"
- **Durable Medical Equipment** (walkers, canes, etc.)
See your local pharmacies and drug stores
Or Search "Durable Medical Equipment in CT"
- **Home Modification**
AARP, Road to Livability, 860-548-3163
- **Senior Centers In CT**
<https://chcact.org/wp-content/uploads/2013/04/ctseniorcentersbytown.pdf>
- **VNA Visiting Nurse Associations**
- **Veterans Administration Healthcare System**
There is much evidence that connects exposure to toxic chemicals in the military with Parkinson's and other neurologic diseases. To learn more, contact:

Diana Richardson, MD, Clinical Director, 203-932-5711 x4724
950 Campbell Avenue
West Haven, CT 06516

Alan Alfonso, Environmental Exposures Office, 203-932-5711
Ricardo Sealy, Veterans Benefit Administration, Hartford Regional Office
555 Willard Avenue, 4th Floor
Newington, CT 06111, 800-827-1000

H. RESEARCH

Today, there are many proven, “gold-standard” therapies for treating the symptoms of Parkinson’s that were only ideas and hypotheses not that long ago. Targeted, supported, and painstaking Research by a literal army of dedicated and talented scientists, medical professionals, therapists and clinicians continues to offer hope to People with Parkinson’s and their Caregivers in the pursuit of living well. Information about recent and ongoing Research advancements is available within the websites listed in Section F of this Guide: “Organizations that Support PD Patients and their Families”.

Many of the promising options currently being developed by researchers are at the stage where volunteers are needed to enroll in Clinical Trials. Please Google “Parkinson’s Clinical Trials in CT” or speak with your neurologist for Clinical Trials that might be right for you.