

Living Well with Parkinson's Disease

10 Things You Can Do Now!

So You've Been Diagnosed With Parkinson's Disease – Now What?

Parkinson's Disease (PD) is a progressive neurological disease, yet most people with PD are capable of living well for many years with a good care management plan. While no therapy has been proven to be “neuroprotective” or “disease-modifying” there is strong evidence that people with PD can improve their quality of life by taking immediate steps to strengthen their bodies and minds. With some of the best neurologists and movement disorder specialists in the country and an active support community, APDA is ripe with opportunities to develop a robust care management team. Keep a positive attitude and jump right in with these 10 steps you can take right now!

1. Partner with Your Doctors

Your doctor may prescribe one or more drugs to treat your symptoms. It's important to follow your doctor's instructions carefully, but recognize that people respond to anti-Parkinson's drugs differently. Do your own research on the classes of drugs available and be prepared to discuss the risks and rewards of each option with your doctor. In some people, the risks of potential side effects may outweigh their benefits. Your doctor needs your input to find the right combination of medicines for you.

2. Assemble a Team

Your care “team” cannot just include doctors and nurses, it must also include other health professionals — such as speech, physical and occupational therapists — that can help you live better with PD. Many people with PD find that these therapies can give them symptom relief, ease pain, and enhance their lives. Even early in your progression, a physical therapist can establish a baseline for observation and help you design an exercise program. Your neurologist should be able to provide recommendations for therapy and, if needed, a referral.

3. Exercise, Exercise, Exercise

While the precise role exercise plays in delaying the progression of the disease and its symptoms is still being researched, studies consistently report that those with PD who exercise regularly do better than those who do not. Many experts recommend intense exercise outside of your normal comfort zone for maximum benefit, but studies also show benefits from less intense activities like walking, tango dancing and tai chi. As always, consult your doctor before beginning any exercise program.

The APDA sponsors many free or low cost community exercise classes. Visit our website: apdaparkinson.org to find a program near you.

4. Eat Right

There is no agreement on any special diet or supplements for PD, but most experts agree that a healthy diet with plenty of water is important. Healthy eating can help keep your bones strong, decreasing the likelihood of a fracture if you fall. It also helps you fight constipation, which is common with PD.

5. Sleep

We all know how critical a good night's sleep is to our health and well-being. However, for those with PD, sleep becomes even more important as the body needs more time to restore and repair itself. Sleep disorders are common in PD, but get your rest when you can!

6. Consider Alternative Approaches

Alternative and complementary approaches to treating PD can include yoga, tai chi, meditation, Reiki or massage. Consult with your doctors or an integrative medicine physician before beginning any course of therapy. Avoid practitioners who claim to "cure" Parkinson's disease, and any who advise abruptly stopping or weaning off prescription medications (unless you have first spoken with your physician).

7. Sign up for Clinical Trials

Scientific research is the key to understanding PD, developing better treatments, slowing disease progression, and ultimately finding a cure. By participating in clinical trials, you play a more active role in your own healthcare and can gain access to new PD treatments before they become widely available. Many clinical trials for potentially valuable new therapies and treatments are developed at great cost but are never completed because of a shortage of willing participants.

If you are interested in clinical trials, your doctors can help you make an informed decision. To find out more about clinical trials in general, and those related specifically to Parkinson's disease, visit:

www.clinicaltrials.gov

www.foxtrialfinder.org

8. Become an Advocate

You become a PD advocate whenever you become involved in activities intended to improve the lives of people living with PD. Whether you choose to raise awareness, fundraise, donate, volunteer, or find your own unique way of lending support, the work of every PD advocate strengthens the voice of the entire PD community.

9. Join a Support Group

The APDA offers many programs for people with PD and caregivers. These programs help families with day-to-day issues, provide a forum for gathering about PD and serve as a place to make new friends who share similar experiences. For many people with PD, their support group is a gateway into the world of PD advocacy, education, and services available in the community.

To find an APDA support group in your area, please visit our website at:

apdaparkinson.org

If you are in an area that does not have a support group, contact us and we will help you get the support you need.

10. Plan for the Future

PD can require you to plan for the costs of medication, home adaptations, insurance and other health care related needs. You may also have employment concerns. Financial planning information and tools are available online and from financial and estate planners, elder care attorneys and disability consultants.

American Parkinson Disease Association

135 Parkinson Avenue

Staten Island, NY 10305

800-223-2732

apdaparkinson.org

Reprinted July 2017