

# 12 THINGS YOU SHOULD DO IF DIAGNOSED WITH PARKINSON'S DISEASE

THE CHARLESTON  
PARKINSON'S  
SUPPORT NETWORK

THE FIGHT IS ON!

You've just been diagnosed with Parkinson's disease. You are shocked, mad, and you don't know what to do next. Here are some of the suggestions from people already living with the disease.

## 1. JOIN A SUPPORT GROUP

West Virginia has seven support groups in six communities: Bluefield (WV/VA), Charleston, Huntington, Bridgeport, Vienna/Parkersburg, and Martinsburg. Go to [www.parkinsonswv.com](http://www.parkinsonswv.com) to obtain details of each group. If you are unable to attend one of these support groups, consider starting a support group in your community or joining an online support group through Facebook.

## 2. MAINTAIN A CONSISTENT EXERCISE PROGRAM/STAY ACTIVE

A steady exercise regime has proven to slow, stop or even reverses symptoms of Parkinson's disease. Whether you work out on your own, with a trainer or attend the free weekly exercise classes in Charleston (held every Thursday at noon at St. Matthews Episcopal Church at 36 Norwood Road), it is important to stay active.

## 3. KEEP A JOURNAL

A journal detailing your journey with Parkinson's disease can be used in many ways. You can bring it to your doctor's appointment to provide a more accurate view of your PD life, including reactions to medications, eating and sleeping habits and a timetable of symptoms and how they have progressed. Use your journal to take notes. It can provide an outlet for emotional stress.

## 4. LEARN AS MUCH AS YOU CAN ABOUT THE DISEASE

Parkinson's disease symptoms are different for everyone and progression of the disease can vary from person to person. So, it will be important for you to understand what to look for and what's important to tell your doctor. That means you need to know as much about PD as possible. There are several organizations/websites that can be helpful as you learn: The Michael J. Fox Foundation ([www.michaeljfox.org](http://www.michaeljfox.org)); National Parkinson's Foundation ([www.parkinson.org](http://www.parkinson.org)), Partners in Parkinson's ([www.partnersinparkinsons.org](http://www.partnersinparkinsons.org)) and American Parkinson's Disease Association ([www.apdaparkinson.org](http://www.apdaparkinson.org)) are great resources to get you started.

## 5. ESTABLISH A GOOD RELATIONSHIP WITH YOUR DOCTOR AND CARE TEAM

Most Parkinson's experts suggest that you choose as your neurologist a physician that specializes in Parkinson's disease. They are referred to as Movement Disorder Specialists or MDS. There is only one MDS practicing in West Virginia. Dr. Anne Killoran is located at WVU Hospital. If you are able to travel, you can locate the closest MDS by going to Partners in Parkinson's website ([www.partnersinparkinsons.org](http://www.partnersinparkinsons.org)). There are neurologists that don't have the MDS designation that have a great deal of experience treating PD patients and they can be a good option when an MDS is not located in your area. As your disease progresses, it may be necessary to add other specialists to your care team. They can include: speech therapist, physical therapist, psychologist, trainer, and more.

## 6. VOLUNTEER IN YOUR COMMUNITY (PROMOTE PD AWARENESS OR OTHER ISSUE)

Many people when diagnosed with PD get mad about their condition. They like to turn that negative energy into positive results and volunteer for a community group within or outside the PD community. The Charleston Parkinson's Support Group organizes many events throughout the year, including: The Fox Trot, Wine & Minds, Papa John's for Parkinson's Research and more. Contact George Manahan if you would like to volunteer at [Manahan@aol.com](mailto:Manahan@aol.com).

## 7. CONSIDER JOINING A CLINICAL/DRUG TRIAL

You can't have medical and drug breakthroughs for any disease without clinical and drug trials. Many researchers have difficulty recruiting patients to participate in their trials. Learn more about medical trials by going to Fox Trial Finder and if you are interested, sign up and you will receive e-mails matching you to ongoing trials: <https://foxtrialfinder.michaeljfox.org>

## 8. TAKE YOUR MEDICATIONS ON TIME

It sounds so easy: "take your medicine on time." But, many Parkinson's patients forget or don't take their medicine. Those with PD can go from feeling great one minute to struggling to take a step the next. Whether you are taking L-dopa, Azilecht, or any of the many drugs to treat symptoms of PD, it is extremely important you take your medicine on time. Set an alarm on your smartphone so you don't forget!

## 9. A BALANCED DIET CAN PROVIDE INCREASED ENERGY LEVELS AND MORE

There is no single diet to treat Parkinson's disease, but a well-balanced diet, including fruits and vegetables, can keep you energized and hydrated. Adjusting the timing of certain foods may be necessary to avoid side effects from medications. Learn more here: [www.michaeljfox.org/understanding-parkinsons/living-with-pd/topic.php?nutrition&navid=nutrition](http://www.michaeljfox.org/understanding-parkinsons/living-with-pd/topic.php?nutrition&navid=nutrition)

## 10. TELLING FAMILY, FRIENDS AND OTHERS ABOUT YOUR DIAGNOSIS

Consider your family as part of your team fighting against Parkinson's disease. No one knows what challenges are ahead and your family will play an important role in your care. If you have the classic symptoms of PD (tremors, slowness of movement, muscle freezing, etc.) it will be difficult to hide it from friends and family. When talking to young children, be reassuring to them, concentrating more about the positive research occurring and less about Parkinson's being a progressive, incurable disease.

## 11. LOOK AT OTHER TREATMENT OPTIONS

Many people with Parkinson's disease can find great relief from symptoms by using alternative treatment options (many times combined with traditional drug therapies). These options could include: Botox, Acupuncture, Massage, Yoga, Meditation, Tai chi and more. Check with your doctor before starting any new therapy.

## 12. MAINTAIN A POSITIVE ATTITUDE/NEVER GIVE UP

There is nothing easy about Parkinson's disease, but many people can still live a productive life with the disease. It will probably mean readjusting career and personal goals and establishing a support team sooner than you expected. Maintaining a positive attitude is probably the most effective therapy in combating the disease.