

PD Diagnosis...What now? Coping, Planning, Support

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You are not alone!

Most people feel very alone when they are given a diagnosis of PD. Remember:

- Approximately 1.5 million people in the US have PD. An American is diagnosed every 9 minutes—that's 164 people each day. That's more than those with MS, MD and ALS combined.
- Parkinson Partners provides education, resources and support in this region for the PD community.



What do I do with this news?

- ▶ There is no right or wrong way to deal with the diagnosis—that goes for both the person with PD and their family—as long as they deal with it.
- ▶ You may find that you are not on the same page as your loved ones. Be careful not to assume.
- ▶ Try to acknowledge not only your feelings but that of your loved ones. Be patient with yourself and with others. You don't have to deal with it all at once. Take your time.
- ▶ As PD progresses, you may find you have to start coping all over again.
- ▶ Share your feelings with someone you trust.

PD: Basic Facts

What are the symptoms of PD?

- ▶ Four major symptoms: *Individuals may have some of these symptoms or all of them.
 1. Slowness of movement and difficulty initiating movement
 2. Tremor at rest
 3. Rigidity (stiffness of muscles)
 4. Postural changes (stooped posture, shuffling and balance difficulties)
- ▶ Other possible symptoms include: depression; emotional changes; difficulty with swallowing and chewing; speech changes (quiet voice); urinary problems/constipation; skin problems; sleep problems; dementia/cognitive problems; orthostatic hypotension (sudden drop in blood pressure when standing up); muscle cramps; pain; fatigue; loss of smell; tiny writing; sexual dysfunction

More PD Facts

- ▶ Cause: The cause(s) of PD is still unknown but among the theories under consideration are genetic predisposition, exposure to environmental toxins and a combination of the two.
- ▶ Biggest Myth: **Levodopa stops working after five years. FALSE** This may be the single most pervasive myth about PD treatment. Many people are reluctant to start taking levodopa because of fear of "using it up." Some physicians also share this "levodopa phobia." The reality is that Levodopa works for decades. Levodopa does not treat all the symptoms of PD, but it dramatically helps the most disabling motor symptoms. Levodopa has been shown to improve quality of life.
- ▶ Another Myth: **Your doctor can predict your future because PD is the same in everyone. FALSE** The reality is PD is highly variable. Even a PD expert has no way of knowing what the future holds for you. You can help to change your future. You can improve PD at every stage by ensuring that you stay fit and receive adequate sleep and proper nutrition. Exercise is particularly important for improving mobility, stamina, mood and quality of life.

Seek Out Information

- ▶ Knowledge is power. Learn more about PD, treatment options, resources etc. Carefully choose where you get your information and take it slow. You don't need to become an expert overnight.
- ▶ Connect with support groups if you are comfortable. Even if you aren't ready to attend meetings, staying informed about events in the PD community can be helpful.
- ▶ Start planning for the future. The one good thing about PD is that it slowly progresses so you have time to prepare for what is ahead.
- ▶ Start exercising. Every neurologist recommends this. There are several local programs. List on the information table.

Your Neurologist...Your Partner on this Journey with PD

- ▶ Is the neurologist that diagnosed you the right doctor for you? Any insurance issues?
- ▶ Does this doctor have experience treating PD?
- ▶ Are you comfortable speaking with your doctor?
- ▶ Do you feel respected by your doctor?
- ▶ Are questions answered to your satisfaction or do you come away from a visit feeling that you have not been taken seriously?
- ▶ Can you get in touch with your doctor between visits?

Treatment Options

- ▶ Make sure you and your family understand the diagnosis and treatment plan.
- ▶ Ask questions. Be honest when answering the doctor's questions. You are only hurting yourself if you aren't telling the doctor the full story.
- ▶ Seek a second opinion, if you like.
- ▶ You must be pro-active. Do not expect that someone will make decisions for you or tell you what to do. You will be asked what YOU want to do.

Tracking your progress

- ▶ Know you will be asked to repeat the same info over and over. Do not assume anyone will have thoroughly read your/your loved one's file (some do, some don't). Consider writing a short summary of medical events to avoid missing any important info.
- ▶ Keep a diary/calendar. Don't rely on your memory.
- ▶ Keep a list of ALL medical providers and ALL medications, including over the counter, vitamin, herbal supplements etc.
- ▶ Keep a copy of insurance information and emergency contact information.

Home Modifications

- ▶ Now is the time to take a good look at your home. Will it work for you in the years to come? Do you have a 1st floor bath and bedroom?
- ▶ Are there easy fixes you can do now?
- ▶ The best time to deal with concerns is BEFORE there is a need or crisis.
- ▶ Think long term for both the person with PD and the spouse.
- ▶ Look into 3rd party funding for big projects.

Legal and Financial Documents

- ▶ Do you have a will, living will and power of attorney (POW)?
- ▶ Is your spouse/POW familiar with your financial situation? Do they know where important documents are kept? Do they know your wishes?
- ▶ Seek the advice of an attorney that specializes in estate planning.

Getting Support

- ▶ Support can mean different things to different people. Family, friends, neighbors, clergy, personal faith, support groups, community resources can all be sources of different types of support.
- ▶ Figure out how and when to tell others. Remember, often the fear of telling is worse than actually sharing the news.
- ▶ When people ask you what you need, tell them. Those that care about you are looking for ways to help. It is not a sign of weakness to reach out to others. It is not realistic to think you can do everything on your own.

Getting Support cont.

- ▶ Remember that your spouse/loved ones may need something different. That is OK. There needs to be a balance so both party's needs are met.
- ▶ You are not being a hero by trying to do everything on your own. You are robbing yourself of precious energy you need to focus on staying well, or in the case of caregivers, to help your loved one.

Support Groups

- ▶ Parkinson Partners has a listing of all area support groups in our monthly newsletter. Each has a different “feel.”
- ▶ Support groups can be a safe place to share fears, frustrations and get suggestions from those that truly understand.
- ▶ Often there is fear in seeing what might be ahead.
- ▶ Remember everyone is different and you will not be on the exact same path as anyone else.

Your Plan “B”

- ▶ Most of us have a Plan “A” for when things are going well, but what happens if something changes?
- ▶ What if you have a fall, injury or your health took a turn?
- ▶ What if something happened to your spouse/caregiver?
- ▶ You need to have a back up plan in place in case of emergency.
- ▶ Make sure your family and support system know what the back up plan is.

Plan “B” cont.

- ▶ Look into community resources (VA, GECAC, County Center on Aging, CRI etc.). Even if you don’t need them now, it is a good idea to get connected.
- ▶ Investigate support services so you have a plan if you need to utilize them. Services could include: cleaning services, lawn care, snow removal, errand services, home repairs, pharmacy delivery, transportation services (LIFT, bus, taxi etc.), meal prep, home health care aides, nursing services, therapy etc.

Be Prepared to Adapt Your Plans

- ▶ What works today may not work in the future. Not only can your needs change but so can your attitude. Be open to new things.
- ▶ Keep communicating with family.
- ▶ Remember that spouses/caregivers need a break, get sick and also need to be considered.

Advice for Caregivers

Be patient – some tasks may take longer to do

Help PwP to help themselves

Maximize Independence

PwP may need more help at certain times of day

Ability to perform tasks may fluctuate with symptoms

Caregiver Care

- ▶ Keep yourself emotionally and physically healthy
- ▶ Reserve enough time for your own interests
- ▶ Recognize that emotions such as guilt and resentment are normal
- ▶ Be aware of signs of depression and get help
- ▶ Attend support groups to discuss problems
 - ▶ Others may be able to share solutions
 - ▶ Contact Parkinson Partners for group information

Questions

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