



Capital Area Parkinson's Society

March 2014 Newsletter

P.O. Box 27565, Austin, Texas 78755-2565

www.capitalareaparkinsons.org

Sharing Your Parkinson's Diagnosis

Michael J. Fox Foundation

How Will This Affect My Relationship With My Spouse?

Think of yourself and your partner as a team. Be honest about what the doctor says, but reassuring. Talk openly about your questions and fears. Together, you will be able to deal more easily with Parkinson's disease.

What Do I Tell My Children?

Focus on reassurance. The older the child, the more open you can often be. Present the reality of Parkinson's disease as a progressive, incurable disease, yet focus on the optimistic truth that scientists are speeding toward breakthroughs more rapidly than ever.

What about Telling Teenagers?

Telling a teenager may be more difficult so be forthright, open to questions, and honest in your answers. If you don't know, be willing to say you don't know. Reassure them that the disease progresses slowly and that new treatments are under study. Give them some sense of control by letting them exercise with you or research questions online together.

What about My Adult Children?

Depending on your age and theirs, the issues may be more about your inability to drive or live alone. Focus on remaining forthright, optimistic and open to questions.

What Will My Parents Think?

It will most likely be difficult to tell your parents and difficult for them to hear it. Frequently, parents feel guilty, frustrated or powerless. Denial is a common defense, which often feels like a betrayal, but don't give up. Given time, parents usually become supportive in whatever ways they can.

How Can I Be Expected to Communicate in an Effective Way When I'm Dealing with So Much?

Many people prefer not to talk about their Parkinson's disease, but those who are able seem to find it less burdensome. Plus, the disease rarely affects just one person. Communication ensures that misunderstandings are kept to the minimum.

Why Do People Think I Am Unhappy or Angry When I Am Not?

Many patients have stiffness and rigidity in their muscles, including facial muscles. Muscles tend to move with difficulty, lacking subtlety and fluidity. Explain to people that your body language "lies," and it is just symptoms of your Parkinson's disease.

Why Are My Friends Acting So Strange?

If every conversation you have with friends is about Parkinson's disease, try talking about the latest movie or the vacation they just took. Having Parkinson's disease is not a license to ignore or dismiss the needs of those around you. Support groups are perfect places to discuss your disease.

What Do I Say to Friends and Acquaintances Who Don't Take My Parkinson's Disease Seriously Because I "Look So Good"?

For many people, "you look so good" seems the safest and least awkward comment they can make. It minimizes the seriousness of your illness which could be incorrect. Putting yourself in the shoes of the person making the comment can make a significant difference in how you react. Again, communication is the key to understanding.

Sometimes I Get Angry or Irritated Because People Just Don't Seem to "Get It"

Frustration with others often subsides when you show greater compassion for how they are dealing with your disease. It is also important to remember that having Parkinson's disease is not an excuse to be less than civil to your

friends and loved ones. Try to recognize the source of your frustration and acknowledge the role of your own actions in creating certain barriers that prevent others from "getting it."

What Can I Say or Do When Strangers Notice or Make Comments About My Symptoms?

The more at ease you are with the fact that you have Parkinson's disease, the easier it will be to take these moments in stride. You can also share concerns like this one at a support group meeting or in an online chat to enjoy the benefit of others' experiences. How Do I Deal With People Who Try to Do Things for Me That I Would Rather Do Myself?

Remember that most people won't know whether you want help or not until they ask, you ask, or they try to do it for you. They can't read minds. Your response will depend on a realistic assessment of your need at the moment and your feelings about the offer of help. Try out responses (yes/no/thanks, but I've got it), and see which works best for you.

For the unedited article, please visit <http://www.michaeljfox.org/understanding-parkinsons/living-with-pd/topic.php?share-your-diagnosis>

Saturday
May 3, 2014
Dallas, Texas



The Davis Phinney Foundation and our Texas partners invite you for a moving day of information and inspiration from leading Parkinson's movement disorder neurologists and physical therapists.

It is free for people with Parkinson's, their family and care partners, but you must register to attend at:

<http://www.davisphinneyfoundation.org/victory-summit>.

More Ways to Help CAPS

AmazonSmile Purchases

Do you ever make purchases on Amazon? If you enter www.smile.amazon.com and then shop, Amazon will donate 0.5% of the price of your eligible AmazonSmile purchases to Capital Area Parkinson's Society. You just have to choose us as your charity of choice. We received \$10 after one member pointed this out to us. With multiple members using this service our monthly donations will surely increase. Thank you in advance for helping out with this!



Amplify Power for Parkinson's! March 20-21, 2014, 6PM-6PM

Power for Parkinson's will be part of Amplify Austin this year. This is an event of *I Live Here, I Give Here* when over 400 non-profits are part of a 24 hour giving campaign to raise funds to make Austin a better place to live. If you love PFP and wish to see it thrive, please consider a donation to our program and encourage your family, local businesses and others to make a contribution to this unique event. Look for us at <https://amplifyatx.ilivehereigivehere.org/powerforparkinsonsCAPS/overview>.

Facebook and T witter

Like us on Facebook and Twitter and find the latest information, ways to volunteer, and more. www.facebook.com/CapitalAreaParkinsonsSociety and www.twitter.com/CAPSAustin

March Membership Meeting

Saturday, March 15, 2014 ■ 2:00 p.m.

The group at Austin Neurology & Sleep Associates is going to present a panel discussion on “Topics to Think About in Parkinson’s” with subjects ranging from what affects my balance, what are my treatment options, what affects my memory and what causes fatigue.

Dr. Iris Wingrove attended medical school at the University of Texas Medical Branch and did her residency at the Mayo Clinic. **Dr. George Petroff** attended medical school at the University of Texas Medical Branch and did his residency and fellowship at the University of North Carolina. **Dr. Michael Hummer** attended medical school at the University of Oklahoma and did his residency at Bernalillo County Medical Center. **Dr. Pamela Howard** attended medical school and residency at the University of Texas School at Houston and did her fellowship at Wake Forest University.

Medical Office Building, St. David’s Medical Center, 5th Floor Conference Room, 3000 N. IH-35

Our program is followed by a potluck meal. We appreciate your potluck contributions.