

How to Manage the Cognitive Challenges of Parkinson's Disease

Technology Tricks

- We use an iPad with a keyboard attached, which can help those who are losing dexterity in hands and fingers. At home: you can link an iPhone to the iPad. Calls will ring and can be answered on the iPad! (Mark, care partner)
- If I'm out of the house, he often doesn't answer when I call, so instead I use Alexa. There is a feature on the Alexa app in which I can talk on my phone, and my voice comes out of Alexa in my house! He can respond back through Alexa. (Ellen, care partner)
- I have drawings with arrows and notes in numerical order for how to use the TV remote and how to make calls on his iPhone. So, when he's stuck, I don't get frustrated at repeating myself, I ask him to look at the picture instead. (Ellen, care partner)

Frequent Physical Exercise

- I exercise regularly and daily fast walking, rock steady boxing, weights, and mild yoga. (Debra, person with PD)
- Serious exercise helps calm me and helps me think more clearly (Paula, person with PD)

Mental Exercise

• I take an online language class in Spanish, so I am learning something new. I read a book about keeping your brain active. I learn to do things that are new – like wear my watch on a different arm for a week at a time or find a different way home from the grocery store or my mom's house. I try to train my brain to learn new ways of doing routine, everyday things that it currently does on autopilot. Every day, I do a crossword puzzle and/or a word game. (Debra, person with PD)

Task Management

- When you set off on a task, use self-talk to keep the momentum going. Repeat: "I'm going into the kitchen to get a banana. I'm going into the kitchen to get a banana" as a reminder to oneself while enroute. (Mark, care partner)
- Before leaving my room or going to bed, I circle the walls of the room in my mind, taking care of each task in its turn. (Carolyn, person with PD)
- · I keep a list of things to do on the counter and only do what I feel I can do. (Paula, person with PD)
- I jot down everything when I think of it before it gets away from me. (Carolyn, person with PD)

Simplifying Day-to-Day Chores

- With our lives becoming technically more complicated, I've found that eliminating things that are no longer necessary makes everything less confusing. I've modified my household inventory to the necessities only. (Paula, person with PD)
- I haven't grocery shopped in years. I order online. Stores overwhelm me. It costs a little more to order online, but I believe I compensate for that by not being in the store buying things I don't need. (Paula, person with PD)
- My husband has mild dementia but wants to continue helping around the house. For a while I just did it all because I had to give so much instruction and oversight, it was just easier to do things myself. But he still wanted to help, so I figured out what he can do that is helpful to me. For example, I list items to be dusted and put a number and a box by each one. That way, he can check off what he has done already. Lists help him organize himself and eliminate the need for me to nag I simply tell him to check the list instead. Sometimes I give him a task that he can't accomplish. If this is the case, I have learned to make it my job and let it go. (Ellen, care partner)

Food and Nutrition

- I follow the <u>Mediterranean-Dash < https://www.apdaparkinson.org/article/mind-and-mediterranean-diets/></u> eating plan. I have lots of color on my plate at every meal. I strongly believe there is a connection between the gut and PD, and the gut and cognitive health. (*Debra, person with PD*)
- I have changed my diet to focus on plant-based foods. I believe that helps me feel better. Learning to cook a different way is a new hobby. I call cooking "exercise" and it is challenging. (Paula, person with PD)
- My tremors are intense on my right side, particularly my right hand. I am training myself to eat with my left hand this is good training for my brain and the bonus is, using my left hand makes getting soup into my mouth a lot easier! (*Debra*, person with PD)

Setting Boundaries with Others

- I try to simplify my life. I come first in every decision. I don't allow anyone to interfere with me caring for myself. I limit my work or involvement in something if I feel it might overwhelm me. (Paula, person with PD)
- I've learned to say no without offending people. (Paula, person with PD)
- I don't go anywhere I don't need to go because life seems to fill that time with things I couldn't anticipate. If I don't push myself to do unnecessary things, then I will still have the mental energy for those things I did not know were coming. (Paula, person with PD)

Medical-Related Advice

- Please make sure that when you no longer need your brain (after you die), that you have done the very easy paperwork to
 donate your brain < https://www.apdaparkinson.org/article/brain-donation/> for Parkinson's disease research.
 Your brain might be the key! (Bob, person with PD)
- It's a good idea to start to shine light on MCI. It seems like MCI is often not discussed that much and we just jump ahead to dementia. People can be defensive and emotional about being made aware of the fact that they aren't as sharp as they were before. But we need to normalize the discussion around this topic so that people can get the help that they need and live their best life! (Barbara, health care professional)
- One of the problems I see over and over is that the person with PD knows intellectually that they need to do something big and important, such as changing living arrangements, or updating legal documents, but has major problems in organizing and thinking about what to do. It might be apathy and trouble initiating, but it could also be unaddressed MCI. (Barbara, health care professional)
- Realize that there are things you can do to help you with your cognitive challenges! Sometimes, people seem resigned, are afraid that it is only going to get worse and have no idea what to do about it. I suggest that if you are concerned about your cognition, you get a baseline evaluation and undergo cognitive rehabilitation. Follow the advice given, which may involve doing mental exercises. Note that the advice may require someone to help set up the appropriate accommodations. For example, the advice might be to set up medication alerts on a smartphone and the person with PD may not be able to do this without help. A friend, relative, care partner, or social worker may need to be recruited. (Barbara, health care professional)

General Advice

- I keep my mind on where my feet are, so I stay in the present. I try not to drift off into the future because worrying never pays off. (Carolyn, person with PD)
- I take everything slower. (Paula, person with PD)
- I laugh at my forgetfulness often. After all, it is funny at times. (Carolyn, person with PD)

Tips and Takeaways

- · Always bring any new symptoms, including cognitive changes, to your doctor's attention
- · Small changes in your routine can have a big impact on quality of life in PD, especially when dealing with cognitive issues
- · People with PD are often the best source of information about how to live well with PD
- Joining a support group < https://www.apdaparkinson.org/community/> is a good way to hear (in real time) about the strategies that others use to overcome the challenges of life with PD, and share some tips of your own