Adult Children Private Facebook Group

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PMD Alliance’s Adult Children of People with Parkinson’s Facebook group offers an important forum for discussion, learning, and building support. Using an UX (user experience) model of design and the value proposition canvas, PMD Alliance created this group to address this population’s specific needs and pain points. In addition to conversations among the members, PMD Alliance posts regular information about treatments, tools and assistive devices, and medical professionals that help them support their family members navigating PD.

My father was diagnosed with Parkinson’s a few years ago and it’s really taking a toll on him as he is very depressed and has thought about ending his life. We as a family have never experienced anything like this so it is all new to us and we are all trying to understand and help my father understand what’s going on. Don’t have anyone to really talk to about anything that happens or get advise from as we all experience what’s next to come.

Feeling frustrated, angry and sad. How do all of you cope? My Mom is my PWP and she is still living with my dad, who is her primary caregiver. Mom is in stage 3 PD with moderate dementia. She has taken on a Jekyll and Hyde personality and it is killing my dad. He cannot get through the idea that it is the disease or it is something he is doing to his wife. They are in a 24/7 mental care unit for 10 days and my sister is in xx. I visit my dad at least once a month (a lot of flying). I feel like an orphan who’s parents are still alive. Sorry, just needed a place to say all of this.

We are glad you joined. I have learned that when someone has Parkinson’s Disease the whole family seems to be affected. Are you going to see a Dr. for depression? On time medication schedule is a big deal and not having protein meal around medication is important to uptake of med. If you have specific questions just throw them out there and we will see if we can help you understand what happening or suggest what to do.

This is definitely challenging but this group always reminds me we aren’t alone. Thank you.

This is the place to share how you feel. I’m so sorry. That is incredibly tough. You will figure out what’s best but of course this is devastating for each of you.

My PWP is my Mother. She is in a care facility as she cannot take care of herself and her husband is in poor health too. I was going to send her a floral arrangement for Christmas but now she has hallucinations of snakes/frogs being in her plants that hiss at her. Everyone is crazy who can’t see them (everyone is crazy) I’m clear across the country but want her to know I’m thinking about her. This is so challenging—Anyone else dealt with this?

We want to be sure you know that hallucinations and delusions are a common symptom of PD and can be tied to the disease and/or medication. There is a Parkinson specific medication for this symptom. It is very important for the Parkinson doctor your dad sees knows about this. If you need more help please feel free to call us at 800-256-0966, we are here to help!

My dad had been hallucinating for a while and became aggressive in the middle of the night, and tried to call 911 because he thought bad people were in the house. It is unfortunately why he went into the 24/7 Mental Care unit for 10 days. His sleep patterns were way off and the medication was just not helping. I do have the laminated emergency course of action template, I think that similarly would help. Because the stress on my mom is probably one of the biggest concerns at this point. I’ve done to terms with my dad we’re just really worn out on our end.

Share with your children and it’s open to all adult children!

Visit Facebook/PMD.Alliance to request to join.