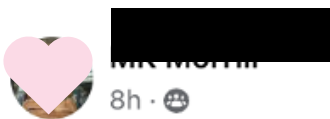




HOW TO HELP YOUR CAREGIVING MOM WITHOUT GETTING OVERWHELMED YOURSELF

If one of your older family members has Parkinson's (PD), you are probably aware of how the disease impacts a person's physical abilities. The stiffness, shuffling gait and loss of balance are the most familiar aspects of this common condition. However, Parkinson's disease affects much more than just mobility and flexibility. There are subtle symptoms which alter daily life of the caregiving partner as much as the PWP's (the Person with Parkinson's).

Lois' husband has PD. Here's what she went through last Thanksgiving.



We've just had 19 family members for four days over Thanksgiving and I have never felt so alone. I tried to talk to some of them about the changes in my HWP (their father/grandfather) and the toll it has taken on me but, understandably, their sympathies lie with him and what PD is doing to him. They did some great service for us by cutting and splitting wood - a task that is getting harder for him to do - and for which I am so thankful. But I felt invisible. Cooking three meals a day for that crew and not one offer of help with cleanup, even if it were just to keep me company. It's not the work of it all (well, maybe a little) but feeling so alone in it. And that doesn't even take into account the preparation it takes before they ever arrive, again, by myself because HWP doesn't do anything to help. Again, I feel so alone. And, sometimes, I think they don't believe me in regard to his decline because he is able to force himself to do more when they are here than he does when they are not. I have decided that I cannot vent or complain or lean on them, so here I am, looking for a listening ear in this group.

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65 Comments



HOW TO SAY IT A CONVERSATION GUIDE

From Terri Pease, Ph.D.

Seabury House

Lois' experiences during the holiday weekend reveal the impact of the non-motor symptoms of Parkinson's:

“HWP doesn't do anything to help.”

People with Parkinson's Disease often lose motivation and interest in the everyday routine activities of life. Even before their motor symptoms make it hard to carry out tasks around the house, they develop a kind of apathy and emotional disconnection from their daily lives and relationships.

“He is able to force himself to do more”

Like many people in the earlier stage of PD, Lois' husband exerted himself to mask the symptoms of his Parkinson's. It's common that, when family or friends come around, the PWP can spend a lot of energy to do more and seem healthy. PD doctors call this “showtime.” However this effort can be too much for a PWP to keep up all the time. Once visitors leave, the PWP can be exhausted and disengage even more, leaving their partner feeling even more lonely unappreciated.

“I have never felt so alone. . . “I felt invisible.”

Lois described an experience that is shared by many Parkinson's caregivers. Caregivers tell us how hard they work really hard to keep their loved ones with the disease functioning as well as possible. They take on more and more of the managing of daily life. At the same time the emotional withdrawal that PWPs go through means that their life becomes even lonelier as time goes on. They give more, even while PD steals their partner's ability to acknowledge what they are doing, or to offer even mild support or connection. That feeling of working so hard to mask the symptoms and keep their PWP seeming as well as possible, and at the same time being unseen, causes a lot of suffering among Parkinson's caregivers.

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“I think they don’t believe me. I have discovered that I cannot vent or complain or lean on them.”

So much of this dynamic – a caregiver working extra hard to keep things going, a PWP who has less and less affection, interest, or attention to give back – is invisible to friends and family. Many PD caregivers talk about this sense of isolation as being one of the greatest burdens. Family see things seeming to go well and don’t want to intrude, so they don’t think to offer the support of washing dishes, doing a grocery run, or cutting the grass, or just (and maybe most importantly) being a listening ear.

How you can help.

There are two important things that you can do to help your family member who is caring for their loved one with Parkinson’s Disease

Believe the caregiver

I think the most important thing you can do to help the PD caregiver is to take them seriously, to listen to what they are telling you, and to be emotionally available.

Don’t make them do the work of asking for help.

Caregivers work almost as hard as their PWP to mask the symptoms of PD. They want to protect their partners from the embarrassment and difficulty of having others know how strongly PD is affecting them. Having to ask you for help is one more burden – what some people would call *emotional labor*. Instead, figure out what you can do.



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HERE ARE THINGS THAT WOULD HELP

1. *Be the reliable ear. Make up your mind to spend an amount of time, maybe an hour a week—every week-- just listening and believing what the caregiver is telling you about her (or his) life. You don't have to offer advice or suggestions. You don't have to fix anything. You just have to care enough to hear about her life.*
2. **When you are running errands for yourself, offer to piggyback something for the caregiver. If you are going to the supermarket or post office or dry cleaner, tell them when you're going and ask if there is something you can do for them.**
3. *Come by for a visit, bringing a coffee and snack. Clean up after yourself before you leave.*
4. **Tell the caregiver when you are available to come and spend time with the PWP so that she can leave the house, or hole up in private, or take a nap.**
5. *If you go on an outing with the PD couple, take on watching over the PWP so the caregiver can enjoy the outing and not just be an attendant.*
6. **If they have a paid in-home caregiver, invite the partner to go out to a movie, or a sporting event, or a hike, and pay for the extra hours of their familiar caregiver's time.**
7. *Pay for a regular cleaning person to come to their house. Or be that person yourself.*
8. **Research local laundry services and give them a gift card for a few loads a month. Or tell them when you will can come by and wash and fold laundry.**
9. *Give the caregiver a gift card, and the free time to go out and spend it.*
10. **Be sparing in how much you share about your own exciting vacations or adventures. Share enough to let them know about the fun, but not so much that they feel the losses that PD has caused in their live.**
11. *For special days (birthday, anniversary, Valentines Day) help the PWP to select and present a gift for her.*



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HERE ARE THINGS THAT WOULD HELP

12. Come by regularly to spend the evening with her—learn the bedtime routine and help the PWP get used to you as a “second person” who can take on some of the caregiving.

13. If you have small children, make short simple videos of them talking to the caregiver—show her one of their toys, or show off a new skill. Make sure she knows how to access the video.

14. If you have older children, encourage them to get comfortable spending time with the PWP and the caregiver, so that they can be a presence, can do some of the heavy-lifting, and learn about how to care for others who probably once cared for them.

15. Learn the routines so that you can be the backup caregiver. In an emergency someone else needs to know what to do.

16. Without making a big deal of it, start to get information about local resources for out-of-home care, so that if this info is needed, she doesn't have to start from scratch.

17. Ditto for palliative care and hospice services. Their quality varies greatly. Start with non-profit organizations. Have information at the ready for when the caregiver starts to need it. If you have been listening, you'll know when that is.

18. Order the Aware in Care hospital kit for them. The PD Foundation created it to help when a PWP needs to go to the hospital. Read the information yourself, then help get it filled out and set up. (Add a phone charger and cable, a medication organizer, a novel or puzzle book, spare reading glasses, a snack or two, a pre-paid card with \$20 to \$30 for emergencies.)

19. Bring your camera and (with permission) take candid pictures of them together in the good moments—such memories can be priceless.

20. Offer to buy and wrap the gifts she wants to bring or send.