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How to Address Prominent Caregiver Challenges

NOVEMBER IS NATIONAL FAMILY CAREGIVERS MONTH



Parkinson's Outcomes Project Links Age to Increased Risk of Caregiver Strain

Caregiving for someone with Parkinson's disease (PD) can be an incredibly challenging task.

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The National Parkinson Foundation (NPF) decided that caregivers needed their own summit with no question or topic off limits. This September we did just that and hosted our first-ever Caregiver Summit with the goal of helping caregivers focus exclusively on themselves. Keynote speaker Susan Imke, FNP, GNP-C, from Kane Hall Barry Neurology, spoke about caregiving choices and challenges—emphasizing ways that a care partner can

avoid self-neglect that leads to compromising physical and emotional health while simultaneously providing consistent, optimal care to their loved one with Parkinson's disease (PD).

"Taking care of someone with Parkinson's is a journey in which a caregiver naturally has a lot of concerns, questions and the need for outside support and guidance," Imke said. "Each phase of Parkinson's comes with new caregiving challenges."

Imke identified the top caregiving challenges and ways to work through them:

➔ **The Realities of Privacy Challenge:** Everyone needs personal space. When a spouse becomes a caregiver and retirement coincides with PD, privacy can become infringed upon for each person.

Tip: Even during early PD stages, care partners should enjoy time alone. Establish a rule, such as one hour a day, half a day

Spotlight on Moving Day®

Ever since Carey Durham was diagnosed with Parkinson's disease (PD) three years ago she's been hoping that Moving Day®, a walk for Parkinson's, would come to her area.

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How to Address Prominent Caregiver Challenges

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per week, one long weekend quarterly. Identify surrogate care options early to ensure you get that alone time.

- ➔ **Communication Challenge:** Some people with PD experience a weakened voice and start to minimize talking, depending on non-verbal communication.

Tip: Be proactive. Have an intentional conversation sitting face to face without distractions; speak up; wait for the speaker to finish his or her sentence before responding and keep an open mind.

- ➔ **Mood Disorders Challenge:** Apathy, anxiety and depression can all be PD symptoms, but caregivers can suffer from these too. Anxiety is common among seniors as it can manifest from worrying, stress and insomnia.

Tip: More than 60 percent of people with PD suffer from clinical depression over the course of PD progression. They are not alone. Neither are you. Find a support group. Anti-depressant medications combined with counseling are more effective than medication alone. Also, never underestimate the power of exercise as an antidepressant.

- ➔ **PD Associated Psychosis Challenge:** About 20 percent of all people with PD experience some form of hallucinations or delusions, and the number increases the longer the person has PD. Psychosis can present caregivers with a new set of challenges.

Tip: While incredibly difficult to witness your loved one see or believe things that are not real, it's best not to argue with them mid-episode. Try to also reinforce desired behaviors every time, anticipate physical needs and keep daily routines.

- ➔ **Caregiver Health Challenge:** Caregiving 24 hours a day, 7 days a week is not a care plan, nor is it healthy.

Tip: Improve your health by taking care of yourself. Keep your own doctors' appointments, drink more water and begin or maintain an exercise routine.

- ➔ **Golden Years Challenge:** Caregivers can feel guilty planning for the future.

Tip: It's okay to plan ahead. Advanced directives are best done in advance and can be done at any age or stage of PD. Designating a health care surrogate in the event of an emergency helps reduce stress later on.

- ➔ **Caregiver Sanity Challenge:** Pushing through and never evaluating mental health can lead to caregiver fatigue and impending health issues.

Tip: Regularly give yourself a candid analysis of what you can and can't do as a caregiver. Consider finances, heavy lifting ability, sleep and nutrition in your analysis. All caregivers need to establish a dependable support system to allow themselves a respite from giving or supervising care. Re-energize by doing something you enjoy.

- ➔ **Long Distance Challenge:** Caregivers who live far away.

Tip: Talk often on the phone if possible. Send cards or flowers if not. Don't settle for email and always show appreciation to the primary caregiver. Say yes to periodic respite care by insisting and getting on a plane to see your loved one at least once a year to become the back-up caregiver.

Susan Imke spoke at the 2016 NPF Caregiver Summit. She is a Family and Gerontological Nurse Practitioner who specializes in Neurology of Aging, with a primary focus on PD and neurodegenerative disorders.



Susan Imke, FNP, GNP-C

For more information on navigating emotional, financial and physical caregiver challenges visit www.parkinson.org/caregiving.



Caring and Coping

For your free copy, call the NPF Helpline at 1-800-4PD-INFO

To read online visit www.parkinson.org/pd-library.