Jennifer Irving – Father diagnosed in 2009

Jennifer’s father was diagnosed at age 52 while he and Jennifer’s mother lived on a different continent from all of his children. Currently he lives in Sydney, Australia and Jennifer lives in the United States.

Jennifer shared that their relationship was challenged in earlier years because her father wasn’t very expressive. Once his diagnosis clarified that this characteristic was part of his Parkinson’s symptoms, they were able to heal and begin rebuilding their relationship. Her decision to move even farther away from her father, was the toughest of her life, but her father supported her decision fully. This decision also came with complications as she intended to remain an active part of his care and support team.

Jennifer’s advice to loved ones living apart from their Person with Parkinson’s (PwP) who would like to remain engaged:

• Cultivate a support system for yourself
• Offer something to engage your PwP — projects, mutual interests
• Use the new technology available to stay connected — Zoom, Teams, FaceTime
• Check-in as regularly as possible — this helps to normalize the disease progression and makes it easier to navigate the process
• Consider ways to ease the pressure on the in-person care team — sometimes as easy as asking how they are doing
• Discuss honestly how you would like to be included and what you can offer to the team — e.g., parents and older family members often protect younger family members from harsh realities
• Create care provider touch points — establish a direct relationship with them if possible, send them questions or pass them along via their care partner/caregiver
• Hold your PwP accountable for their own care — sometimes this means parenting your parent
• Get creative — Find ways to connect and engage that you may not have thought of before

• Be okay with not being okay — give yourself some grace and recognize the difficulty of your situation

Maggie Rowland Wortendyke – Father diagnosed in 2014

Maggie’s father lives with her mother in Birmingham, Alabama, while Maggie and her family live in Nashville, Tennessee. She offered tips based on her experience supporting her parents from afar.

How you approach being involved can and should change. Their family experienced an evolution from 1) initially not talking about Parkinson’s at all, to 2) talking about it a little and engaging in the community through fundraising, to 3) eventually finding some humor and a way to discuss the disease and her father’s care more comfortably. Maggie’s family allows her father to lead the charge on what’s comfortable, what works and how to adapt to the ever-changing symptoms and needs. Flexibility and a willingness to adapt is key.

Determine what works for you regarding how to actively support your PwP and their in-person caregivers. Having a tangible way to be involved can be key to your own process. Maggie and family began organizing events to raise funds for Parkinson’s research. She also provides emotional support and perspective to the in-town caregivers and family members. She recommends checking in with them before in-person visits to discern how you may be helpful.

Realize that being far away from your PwP can be lonely. Find support and ways to maintain balance. Find an outlet for your stress and be aware of the risk of burnout. Avoid toxic positivity, and allow yourself to have the full range of human emotions in your experience.

“After diagnosis our relationship got better because we knew what was going on. There’s power that comes with diagnosis, as well as a lot of mixed emotions and fear.”
— Jennifer Irving
Recognize that when your loved one does something hurtful or uncomfortable, it’s usually a result of the disease. Parkinson’s changes people and can even change personalities. Learn to discern what is a result of symptoms and may require intervention, and remember to not take it personally.

Jill McClure, Information Specialist, Parkinson’s Foundation – Father, now deceased, was diagnosed in 2007

When Jill’s father was diagnosed her children were small and they were unable to live in the same home. She was very engaged in his care and shared some advice from the perspective of a caregiver from afar and an information specialist.

• Get to know the local resources and care providers — be in contact with those who have boots on the ground
• Be informed about PD and PD-specific help available in your area — signing up for organizational newsletters and notifications can help
• Put yourself out there — actively engage in support groups and other local events
• Engage in care and appointments at a level that’s comfortable for everyone — e.g., care provider communication, medication management, connect with patient portals, establish yourself as an emergency contact, become a primary contact for specialists and providers (Note: Special permissions, paperwork and sometimes legal steps/Power of Attorney are often required for access to patient information and care providers.)
• Take advantage of available technology — e.g., set up apps as medication reminders, sign up for medical alert systems, etc.
• Check in with yourself regarding anxiety and burnout — e.g., self care, make sure you’re not taking on your PwP’s anxiety, make sure you have support to take a break or get help when needed
• Make a choice to stay flexible and adaptable — PD is constantly evolving, and supporting your PwP’s quality of life is too

“It is lonely to care about someone with Parkinson’s who is far away. But just because you feel lonely doesn’t mean you are alone. There are people all over the world in the exact same spot you are.” — Maggie Rowland Wortendyke

Watch the Webinar
https://www.worldpdcoalition.org/3rdcarepartner

Links and Resources:
World Parkinson Coalition – global list of local/regional partner organizations and resources
https://www.worldpdcoalition.org/Resources

Parkinson’s Foundation – help line, care partner resources
https://www.parkinson.org/

Parkinson Canada – help line, care partner resources
https://www.parkinson.ca/

National Association of Elder Law Attorneys (US)
https://www.naela.org/findlawyer

Aging Life Care Association (US and Canada)
https://www.aginglifecare.org/

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