Marc Jaffe

Marc’s wife Karen was diagnosed in 2007 at age 48. Initially they decided to keep the diagnosis secret, even from their children, for personal and professional reasons. At the same time, and without external support, they were acclimating to their new normal.

A new phase of their marriage began when Karen started taking a dopamine agonist and she experienced the side effect of hyper-sexuality. Marc enjoyed this at first, happily accepting their intense sex life as part of his new role, but after several months he began to feel “winded” and concerned. He became anxious and confused about his identity as a husband and man, and he wondered what would happen to their marriage if he decided not to fulfill his wife’s desires.

Marc admits he was relieved when they decided to be open about Karen’s Parkinson’s. They began working through their challenges with a larger community around them. He was able to more fully embrace his role as care partner and find some self-care tools, including discovering meaningful ways to use his experiences. The couple started their foundation Shaking with Laughter to support Parkinson’s research and the InMotion Wellness Center in Cleveland, Ohio. He also used his natural humor and comedy writing talents to write an Off-Broadway play called “Side Effects May Include…. .”

Marc’s advice to care partners taking on the role:

• Find an outlet that works for you. Use your talents and interests to find purpose within your care partner role.

• Shift the focus. Find a different perspective about and outlet for challenges and behaviors that arise. Instead of anger and frustration that you have to face more than anticipated, remember that you are the care partner of someone you love, and it’s an honor to be able to support them.

• Don’t overdo it. It’s possible to perform the role of care partner too earnestly.

• Advocate for yourself within your relationship. Communicate openly about your needs.

Tanya Cluff

Tanya’s husband Paul was diagnosed in 2017 at age 39. Initially, she faced this new role with mixed emotions. Her intention was to be supportive and compassionate, but she acknowledges that she also was managing her own grief about the diagnosis and an understandable emotional rollercoaster, including denial, anger, and eventually acceptance.

Even after educating herself, connecting with her community, and finding a foundation of acceptance, the rollercoaster didn’t stop. When burnout approaches, Tanya experiences a cycle of frustration, anger, vulnerability, loneliness, and fear of expressing herself honestly. While her intention is to be a supportive partner, some days she finds it nearly impossible to find empathy. Counselling is an important part of her self-care that has helped her find more openness and patience with communication.

Tanya has embraced her role as care partner by playing a part in Paul’s exercise and care choices, being his voice when he struggles to communicate, and co-founding Can’t Shake Me, a nonprofit in Leesburg, Virginia.

Tanya’s advice to care partners taking on the role:

• Find a sense of identity and meaning outside of your care partner role. Have your own interests and a distinct awareness of purpose and self.

• Educate and empower yourself to make informed choices on your own.

• Do not compare your journey to others. We all embrace our care partner role differently and at a different pace.

“We call ourselves care partners, and sometimes I think we should call ourselves “don’t care partners.” You have to find the right times to allow the other person to solve things on their own.”

— Marc Jaffe, care partner

What Does Being A Parkinson’s Care Partner Mean to You?

In March 2022 the World Parkinson Coalition launched its third Care Partner Virtual Talk Series. Julie Carter, RN, MN, ANP and Professor Emeritus at Oregon Health & Science University moderated the webinar. The panel of care partners shared their stories with a focus on how they’ve accepted their role as a partner of a person with Parkinson’s (PwP), their sense of identity within it and how they advocate for themselves.
Jayne Calder

Jayne’s husband Darren was five years into his YOPD journey in 2009 when they first met. At first, she was fiercely defensive of him, especially out in public. While this is how she initially coped with and accepted her role as care partner, it began to take its toll on them both. She realized she was letting Parkinson’s take the lead role in their life and their identities.

Jayne was extremely independent and career-focused when they met, and much of her identity was enmeshed with her work. Once she began her relationship with Darren she found her way by using her professional skills within her care partner role. She supported Darren as he began to more fully face his diagnosis and the required considerations, and she took on the responsibility of educating herself and their community about Parkinson’s. These projects became an important part of Jayne embracing her role, normalizing the issues they face, and empowering them both within their experiences.

Darren was part of the now well-known UK-based Stage 2 GDNF clinical trial, an opportunity that Jayne initially resisted. She knew it would require more time and care on her part, not to mention the risks of brain surgery. But she eventually decided that as Darren’s partner she should support his decision. Despite a loss of independence and wellness, it also offered Jayne more opportunities to speak out, advocate, educate, fundraise and share her experiences. Combined with her happy life with Darren, these activities offer meaning within an often challenging role.

Jayne’s advice to care partners taking on the role:

• Learn to live alongside Parkinson’s. Acknowledge it can get the better of you sometimes. Ask for help, forgive yourself, and keep moving forward.
• Take care of yourself first. Listen to your body and understand your needs. Find time for yourself separate from your PwP.
• Do it together. Parkinson’s affects everyone who loves a PwP. Finding connection, love, affection, support and mutual respect are key to staying well and maintaining your partnership.
• Normalize the Parkinson’s experience. Seek confidantes, share honestly, and establish a circle of trust and support.

Watch the Webinar
https://www.worldpdcoalition.org/Webcasts

“Personally I don’t like the “care partner” label. I’m Darren’s wife and I want to be Darren’s wife. I feel more like a guardian or defender. I protect, a bit like a Rottweiler at times.” — Jayne Calder, care partner

Additional Resources:


InMotion wellness center
https://beinmotion.org/

Can’t Shake Me
https://www.cantshakeme.org/

More about the GDNF trail in UK
https://www.gdnf.org.uk/participants/jayne-calder/

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