

Palliative Care is the First Step to Supportive Total Care

By: Lori DePorter

My first experience with the topic of palliative care set the tone of my perception of it for almost ten years. Newly diagnosed with young-onset Parkinson's disease ("YOPD"), I had lunch with another person with YOPD. He said, "You do know...there is no cure—it's all palliative care," which I associated with end-of-life and hospice care. With that, lunch ended, and I put palliative care aside.

Now, one word has changed my perspective—**supportive**.

In the videos offered by PMD Alliance, ["Palliative Care & Chronic Disease Self-Management"](#) and ["Introducing Neuropalliative Care With Dr. Benzi Kluger"](#), Dr. Benzi Kluger says, "Palliative care is supportive care." Support implies help rather than helplessness, and that makes a difference. Palliative care provides extra support to help people live well for as long as possible and can be beneficial from diagnosis to end-of-life situations.

The presentation focused on the importance of palliative care for Parkinson's disease from the time of diagnosis into later stages. It included slides, which made it easy to follow and understand.

Palliative care manages "the total pain" of Parkinson's disease. It includes the physical and non-motor symptoms. However, it reaches beyond them to include many "invisible" yet debilitating symptoms, including emotional and social, and spiritual and practical elements, from depression and anxiety, loneliness and isolation, to a fear of the future.

Palliative care provides the tools to "live with Parkinson's" by providing extra support for the 5 pillars of a team approach to palliative care: (1) non-motor symptoms, (2) care partners, (3) emotional and spiritual well-being, (4) referrals, and (5) advanced planning.

I was surprised to learn that I have been doing palliative care and didn't realize it. I advocate for professional mental health for the patient and the family. I meditate, exercise, see a psychologist regularly, and attend future planning workshops with my husband, Mike.

While I never imagined a topic that I avoided would be true to my mantra that life is different with Parkinson's, but it can still be good, I am grateful for the new perspective. **Seeing palliative care as a supportive, holistic approach motivated me to continue expanding my clinical care to include additional self-care for Lori—the whole person.**

We live in a world where words are powerful—even just one. For me, that word was "supportive." These resources presented palliative care as supportive care, which changed my perspective and encouraged me to learn more. We also measure success with analytics, which don't show how educating and empowering one person matters.

Neuropalliative care is a healthcare concept that gained momentum with the establishment of the [International Neuropalliative Care Society](#) and its mission to improve the standard of care for all patients with neurological diseases. As patients, we must advocate for ourselves and others and encouraging palliative care for all neurological patients at any stage of a disease.

Together, we can use this extra support to embrace the joy in life while also recognizing the challenges Parkinson's brings.

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My husband Mike was struck by Dr. Kluger's slide showing 100% mortality rates worldwide. As a society, we need to be comfortable with our mortality rather than fear it and enjoy the here and now. Remember, palliative care is not the end of our care—it's the beginning of our total care.

With that, I leave you with one final thought ... **"Bloom where you are planted and be present in your life."**

Lori DePorter lives in Pennsylvania with her husband, Mike. She has three grown sons, two daughters-in-law, and a granddaughter. Diagnosed with young-onset Parkinson's disease at 45, Lori became an advocate for Parkinson's and others with disabilities through health and wellness, writing, public policy, and community outreach. She is a PMD Alliance Global Ambassador, support group educator, Rock Steady Boxing coach, and certified personal trainer. She is a published author and shares her story to empower others to see that life with Parkinson's is different, but it can still be good.