INPCS BLOG Featured Neuropalliative Care Champion Series

This year we are starting a new feature in addition to our monthly blogs. The INPCS Featured Neuropalliative Care Champion series will include writings on and/or by an array of champions, includingclinicians, researchers, patients, family members, and anyone who is interested in and/or is an advocate for neuropalliative care. We invite you to read and be inspired by what drives our champions and why neuropalliative care is meaningful to them.

Sandhya and Christine
Co-Chairs, SCC

Featured Neuropalliative Care Champion: Diane Cook

Diane Cook has led and been a part of many initiatives to improve the lives of those impacted by Parkinson's disease. She grew up in both the United States and Europe, an international upbringing that gave her a deep appreciation for diverse perspectives and a compassionate outlook. She built a rich career in international relations and leadership development, but a Parkinson's disease diagnosis in 2008 changed her path. Diane responded by founding the **Parkinson's Disease Self-Efficacy Learning Forum (PD SELF)** to empower others living with Parkinson's through the power of self-efficacy and a supportive, positive approach to care. She has contributed extensively to many neuropalliative care programs, research studies, and co-authored publications that provide vital perspectives on the experience of living with PD. Today, she is a passionate advocate for **neuropalliative care** through the University of Colorado's program, championing the idea that with hope, resilience, and person-centered support, people with neurological illnesses can continue to find joy, meaning, and quality of life even in the face of serious illness.

Diane has written about her journey and we are delighted to share her writings with you in 3 parts that will be posted over the next 3 months.

PART ONE: WHY WE SOUGHT NEUROPALLIATIVE CARE

I was diagnosed with Parkinson's disease at the age of 65, and I've done quite well managing my PD over the last 18 years. My husband has been my care partner throughout. I have the non-tremor, motor-dominant prototype of PD. My biggest challenges have been the management of an ever-changing constellation of non-motor symptoms, in addition to the classic PD symptoms of increasing slowness of movement and mind, impaired posture and coordination, and significant rigidity.

I have always used active exercise as the predominant therapy to keep my PD from progressing too rapidly. However, I began developing severe shooting leg pain 2 years ago that impacted my mobility and ability to exercise. It soon became clear that I needed to find another solution to regain my mobility and keep my PD in check.

Last year, I had a successful lumbar spine fusion. However, at the age of 81, the surgery exacerbated several existing PD symptoms and sparked new symptoms. Morning rigidity has increased, sleeping problems worsened, constipation remains a constant struggle, GI problems require new medications, and my dry eyes have contracted mites. New symptoms have included increasing difficulty swallowing with occasional choking, voice/communication issues, pelvic floor prolapse, and urinary incontinence. There is also the need to continue aggressive work on regaining my strength and addressing the balance, gait, and other ramifications of the realignment of a portion of my spine.

Each of these symptoms requires initial and then periodic visits to the appropriate specialist. Identifying these specialists who have experience treating Parkinson's patients in their area of specialty requires outreach, consultation, and sometimes trial and error. Management of this network becomes more challenging, as does the task of keeping records updated.

Because I was in a back brace for 4 months following a prescribed protocol of not driving and not bending, lifting, or twisting, my care partner had to assume virtually full responsibility for the physical aspects of managing our home. He also needed to drive me to all appointments. It was becoming too much for him. **We needed help.**

Who could I turn to? We needed counsel on fall-proofing our home. I needed physical therapy to learn how to manage daily life with my new restrictive protocols. I needed resources, referrals, and advice.

I was aware of the groundbreaking work in palliative care being done at the University of Colorado, but questioned if I fit into the spectrum of patients they serve? Would help for my care partner be included in the scope of service we might need? We called and set up an appointment.

That call was the best thing we ever did!