INPCS Featured Neuropalliative Care Champion Series

Featured Champion: Diane Cook

With a diagnosis of Parkinson's disease, Diane Cook decided to learn everything she could about the disease. Two years after receiving her diagnosis, in 2010 she developed the Parkinson's Disease Self-Efficacy Learning Forum (PD SELF), basing its approach on psychologist Dr. Albert Bandura's theory of self-efficacy, and the work of Dr. Lisa Shulman at the University of Maryland, who first demonstrated that self-efficacy could improve the quality of life for those with PD.

When asked what motivated her to pursue neuropalliative care, Diane simply said, "Exploring the potentially powerful interface between Neuropalliative care and the patient's role in creating, despite the presence of serious illness, a QOL that includes joy, meaning, love, and growth (in Benzi's words). The combination of a clinician's focus on positive outcomes beyond the reduction of suffering, coupled with tools (such as self-efficacy) to enable patients to create their best possible lives, creates an approach that "supports the full humanity" of the patient in his or her final years."

PART TWO: BEGINNING OUR NEUROPALLIATIVE CARE JOURNEY

At the time we first sought palliative care, my family and I didn't know how much we didn't know. Should an accident have happened or one of us taken a sudden turn for the worse in terms of health, we would have been completely unprepared for this next phase of our lives. Let me explain how this important journey unfolded.

We began by meeting with the Director of our Palliative Care Team. We were given enough time to share our history, values, goals, concerns, and current needs, providing a foundation to build upon. My needs and my care partner's needs were given equal consideration. We felt listened to, which created an atmosphere of openness. We felt understood, which established a level of trust. It was from there that we began to have sessions with members of our team: including a palliative neurologist, a palliative primary care physician, a palliative psychologist, and a palliative chaplain. *The guidance and support we received from the members of this team -- as we defined and designed for ourselves what our future will look like and how we need to prepare to achieve our best quality of life going forward -- is among the best counsel we have ever received.*

There are several reasons we have found this approach to be so effective. First is the professionalism and sensitivity of each team member, who work both in tandem and seamlessly with one another to move us forward. Second is the process of guided discovery and coaching. For example, when discussing my care partner's fear of losing me and possible inability to cope on his own, he was asked, "Where do you find your sources of strength?" By helping him examine for himself what and where those sources are, he has become more aware of the strengths he already has to support himself. This process of guided introspective discovery has helped us recognize our own ability to navigate this somewhat daunting last phase of our lives.

One of the ways palliative care has been particularly helpful to us has been through discussing our goals of care. The discussion of goals of care includes making key healthcare decisions and then making sure they are properly articulated in the critical Advance Directive forms, such as the Living Will, Medical Power of Attorney, POLST or MOST form (depending on state). We discussed the various options several times to ensure we understood the specific implications of our decisions. This was extraordinarily helpful and, in fact, ended with both of us changing our choices. We learned that the POLST and MOST are printed on bright green paper and are meant to be placed on the outside of one's refrigerator, as that is where emergency personnel are accustomed to looking when responding to an emergency. We have now posted our green forms on our refrigerator to ensure that our Advance Directives are followed. This puts our minds at ease, and in fact, we carry these forms with us when we travel to ensure that those with us in the event of an emergency will be assisted by knowing what kind of care we want and do not want.

Another aspect of defining goals of care was defining what is important to us in our lives now as well as the interests and activities that most interest us, so we are better able to envision what we will need to incorporate into our living arrangements and life going forward. Initially, we thought that a retirement living community would best meet our needs. However, further analysis and introspection led us to conclude that, if possible, we would prefer to "age in place." We would like to be surrounded by the special mementos of our life, our books, and the coziness that only our own home can provide. We also wanted to bring our beloved goldendoodle with us, without whom our lives would be incomplete. Each of these options requires a distinct set of steps to move forward. We are both quite relieved that we did not set down the wrong path!

Next month, in Part 3, Diane will share the emotional support and spiritual care she found through palliative care.