

INPCS Featured Neuropalliative Care Champion Series



Featured Champion: Diane Cook

True to her lifelong passion to look for the positive in all challenges, Diane Cook did not let Parkinson's disease deter or cloud her thinking. When asked what inspired her about the Neuropalliative Care community, Diane said, "I have always looked for the positive in any situation, and the palliative care approach of supporting the positive, despite disease, is very compelling to me. And, given my lifelong interest in doing what I can to help others, I have almost seamlessly found myself espousing this palliative care perspective."

This month, in the concluding part of her writings, we invite you to be inspired by Diane's insights on emotional support and spiritual care in her journey.

PART THREE: EMOTIONAL SUPPORT AND SPIRITUAL CARE

Emotional Support

With the added stress of my spine rehabilitation, limited mobility, and an increase in the number and severity of my PD symptoms, new demands were being placed on my husband as a care partner. The realignment of duties and the necessary additional support require effective and sensitive communication between partners. We did not think we were in urgent need of "fixing" our relationship. Still, we were open to consulting the palliative psychologist on the team to ensure that we were doing everything possible to ensure smooth sailing ahead.

We have now had several sessions, both together and independently, and have found them to be extraordinarily useful. We identified several areas that were causing us concern, and it was a great relief to address them directly. We felt aided in this process by the palliative psychologist, an expert in working with individuals coping with the same issues we are. She helped us design some communication strategies, intervention strategies, problem-solving strategies, and resolution strategies to use at these "problem" junctures. We have begun using these with good effect and fully believe they are heading off problems that might have been festering.

It has made this journey of introspection, decision-making, planning, and action one of learning and completion rather than frustration and loss.

Spiritual Care

We have met with the palliative chaplain several times, both together and individually. Discussions included, for example, our purpose in life, what gives our life meaning, what we feel connected to, and so on. These discussions helped us better define and articulate our thoughts on these questions, as well as gain interesting insights and an understanding of some of the differences between my care partner and me regarding what we feel connected to, a topic we had rarely discussed. There is still more exploration to be done to ensure that we meet these needs in our lives ahead. We also spent time individually discussing our personal and different spiritual paths.

We were encouraged to try to express where we want to be spiritually at the end of life, and if we feel there is more work to do to be able to feel at peace with dying. We were also encouraged to think very specifically about the details, for example, what and who we want with us at that time, what kind of mementos, flowers, or music we want, and so on. Taking a clear look at the whole dying process from beginning to end has been very helpful in replacing any fear I had with a better understanding of what happens to the body and mind in the natural course of death

Conclusion

Receiving palliative care assistance is invaluable. We can't imagine designing the next phase of our life, the planning and execution of it, the emotional and spiritual preparation for end-stage living, and experiencing fulfillment and peace at the end, without the experienced, empathetic and loving support that a Palliative Care Team can provide.

It is a true gift and has significantly improved the quality of the life we are living now and how we will live in our remaining years. Gary, my husband, and I are deeply grateful.