Richard Young – Wife Frances diagnosed with YOPD more than 25 years ago

Richard’s wife Frances was diagnosed in her late 40s, and with the disease’s progression she is now living in a long term care facility. His family lives in other regions so Richard and other caregivers have provided care and support to Frances over the years. He and his wife have experienced a myriad of losses as her Parkinson’s progressed.

Richard believes there are two kinds of loss:

Present Moment Loss — This is connected to daily challenges and continuous recognition and management of new symptoms, loss of abilities, and loss of communication.

Anticipated Loss — These are losses connected to all the things care partners may have imagined for their life that are no longer possible — e.g., travel, time with grandchildren, an active social life.

How Richard responds and addresses these losses:

• Collaboration — He engages with his wife’s care team and asks for help when needed. He also includes his wife in the process of discerning her needs and the best way to address their daily challenges.

• Care Partner Support Group — Participating offers him an opportunity to share experiences and connect with others who understand his challenges.

• Adaptation — Speech issues currently make communication particularly challenging for Richard and Frances, so their connection primarily comes through touch.

Nancy Schullery – Husband Steve diagnosed 11 years ago

Nancy’s and her husband Steve have been married for 54 years. His main symptoms are tremor (now largely managed following Deep Brain Stimulation surgery), freezing, balance, tiredness and facial masking. He doesn’t need a lot of personal care.

Nancy and Steve have experienced big changes over the years as a result of Parkinson’s, including role changes, financial responsibility shifts, loss of skills and abilities, loneliness, a slower pace, and a greater need for patience.

Allowing herself to grieve these ongoing changes and losses, and focusing on quality of life have both played a significant role in accepting their ever-changing new normal.

Additional ways Nancy addresses her challenges:

• Recognizing that our Parkinson’s journey is unique; it’s important to identify and face your own emotions and reactions, both together and separately

• Keeping a sense of humor, encouraging shared jokes and reference to special memories

• Having something to look forward to

• Going out even when her Person with Parkinson’s (PwP) can’t – or won’t – and being aware of how long she can stay out comfortably

• Participating in a general and a Care Partner support group

• Using mindfulness tools to help focus on the present moment

Nancy acknowledged the perspective offered by Tom Isaacs’ Parkinson’s Pyramid. The late Parkinson’s advocate, Isaacs, outlined four stages — and their overlapping nature — that many PwPs and their families experience:

1. Shock, Anger and Denial
2. Acceptance and Communication
3. Advocacy and Participation
4. Working to Influence toward a Cure for Parkinson’s

Maggie Parker Ivancic, MSW, LCSW
University of North Carolina Movement Disorders Center

Maggie noted she was inspired to work with the Parkinson’s community because of her connection with her grandmother who had Parkinson’s for more than 20 years beginning in Maggie’s early childhood. She shared some tips for coping with Parkinson’s as a care partner, especially when it comes to later stages of the disease’s progression.

"Give yourself some time to grieve the ongoing losses you see and feel. It's hard to watch as the person you love loses skills and abilities and struggles more and more.”

— Nancy Schullery, Care Partner
Facilitate difficult conversations, including discussions about:

• Advanced care planning
• Medical interventions
• How your PwP wants to be treated when they can’t speak for themselves
• What your PwP may want their loved ones to know about them
• What values are important to keep in mind as the disease progresses

These conversations are uncomfortable, but it’s important to have them early and often, as feelings and desires may change over time. If your PwP isn’t ready to talk about these issues, know that it’s okay and that you gave them the opportunity and space to express themselves. Ask again and be persistent.

It’s important to remember that grief is real and normal, including its cyclical nature. Grieving the losses associated with Parkinson’s does not indicate that you are ungrateful, unloving, unsupportive, or without hope. Your grief is, in fact, a normal human reaction and an expression of love and gratitude for your PwP.

Christina Vaughan, MD, MHS
Neuropalliative Care Section, Departments of Neurology and Medicine, University of Colorado Anschutz Medical Center

Palliative care is both a medical specialty and an approach to care that focuses on improving the quality of life at any stage of a serious illness. It typically involves an interdisciplinary team intended to address the patient’s mind, body and spirit — a medical provider such as a doctor or nurse practitioner, a social worker, a nurse, and a spiritual counselor. This team focuses on four main areas:

• Addressing physical symptoms
• Psychosocial issues — managing practical challenges
• Spiritual wellbeing — including grief
• Future planning

As part of establishing a treatment plan, two of the most important conversations with patients and families include:

• Establishing Goals for Care — ensuring the care plan and services offered align with the patient’s needs, values and priorities
• Advance Care Planning — ensuring the patient’s wishes are known and documented (via Medical Power of Attorney and Advance Directives documents)

Finding palliative care near you depends on what’s available in your country and region, which can vary widely. Proactively asking your current care providers is a way to start.

“When it comes to chronic progressive illness, we’re living in grey. There are lighter grey days and darker grey days and all the shades in between. It’s important to allow ourselves to feel all of it.”
— Maggie Parker Ivancic, MSW, LCSW

Watch the Webinar
https://www.worldpdcoalition.org/3rdcarepartner

Links and Resources:

International Neuropalliative Care Society
https://www.inpcs.org

Five Wishes Advanced Care Planning Program (US only)
https://www.fivewishes.org/

Tom Isaacs’s Parkinson’s Advocacy Pyramid
https://www.parkinsonsmovement.com/toms-advocacy-pyramid/

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