Palliative Care AND PARKINSON’S

Many people are unaware of the type of patient and family-centered care available to our Parkinson’s disease (PD) patients that can optimize their quality of life by anticipating, preventing, and treating suffering. In this edition of The Transmitter, we examine palliative care and the impact it has on our PD patients and families.

Palliative care is specialized medical care for persons living with a serious illness, including cancer, heart failure, chronic obstructive pulmonary disease, dementia, PD, and other disorders. The primary goal of palliative care is to improve the quality of life for patients and their loved ones by addressing physical, emotional, psychosocial, and spiritual needs.

The concept of palliative care was first introduced in 1948 by Dame Cicely Saunders, a British physician, and has grown in popularity over time. In 1990, the World Health Organization recognized palliative care as a distinct medical specialty dedicated to relieving suffering and improving quality of life for persons with a serious illness or injury. Although hospitals in the United States were initially slow to adopt palliative care practices, the field has grown considerably in the last 20 years.

WHAT IS PALLIATIVE CARE for Parkinson’s Disease? By Whitley W. Aamodt, MD, MPH, MSCE

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WHAT IS PALLIATIVE CARE

In addition to improving quality of life by addressing bothersome symptoms and providing support services, palliative care can help patients plan for their future. Palliative care does not replace but rather enhances routine medical care. Important to note is that palliative care is not hospice care. It differs from hospice in several important ways:

1. Palliative care may begin at any stage of disease (from diagnosis through end-of-life) and can be provided alongside curative treatment.
2. If a disease progresses over time and treatments become less effective, palliative care can place increasing emphasis on patient comfort and/or provide referral to hospice care when indicated.
3. Enrollment in hospice care typically requires discontinuation of curative therapies and is only available to patients with a presumed life expectancy of 6 months or less.

Can palliative care be helpful for people with Parkinson’s (PWP)?

Yes! Research has shown that integrating palliative care into existing PD care can reduce symptoms and improve quality of life. Palliative care goals include:

- Providing a diagnosis and prognosis with compassion
- Complex symptoms management
- Addressing social, emotional, and spiritual wellbeing
- Caregiver and family support
- Discussing goals of care (including advance care planning)
- Referring to hospice when appropriate

While many of these goals are addressed during routine clinical visits, some does not always allow for more in-depth discussion. A dedicated palliative care clinic can provide space to review these items in detail, with a team of professionals who work together to address physical symptoms and psychological challenges, offer spiritual and caregiver support, and help patients and families plan for the future.

Who is eligible for the Palliative Care Clinic?

We welcome all patients with parkinsonism at any stage of their disease course. Patients may attend the clinic once, on an annual basis, or twice a year, depending on their needs. Palliative care services are offered in conjunction with regular PD care, and our clinicians will not replace your primary neurologist.

How much does the clinic cost?

Visits typically last from 2-4 hours based on individual needs and interest in working with the therapy team.

How does the Palliative Care Clinic differ from a regular office visit?

During a regular PDMDc office visit, providers usually focus on your diagnosis, clinical symptoms, exam findings, and current treatment regimen. These visits may also include some discussion of how parkinsonism affects your life, activities, and daily functioning, but time may not allow for more detailed conversations on what matters to you most.

The Palliative Care Clinic places less emphasis on the diagnosis and exam and more emphasis on finding ways to improve quality of life for patients and their care partners. While we may offer suggestions on how to adjust your medications, we are most interested in offering additional support to ensure you are comfortable and living your life to the fullest.

In these longer sessions, you can really delve into questions such as: What symptoms are most bothersome? What brings you life joy and meaning? What support services are available for you and your care partner? How should you plan for the future? What resources will you need?

Interested in learning more about palliative care?

Talk with your provider at your regularly scheduled PDMDC visit to see if you can place a referral to the Palliative Care Clinic. You may also contact Suzanne Reichwein at svreichwein@pennmedicine.upenn.edu or Sara Boyer Hughes at Sara.Hughes@pennmedicine.upenn.edu, or call 215.829.7273.

THE ROLE OF A SPIRITUAL COUNSELOR in Palliative Care

By Linda Joy Goldner, MAJS

Patients with movement disorders, as well as their care partners and loved ones, face many challenges, but are not alone. The PDMDC offers a broad range of services and support programs to help address these challenges, from occupational therapy to care partners’ workshops to group recreational activities such as dance and yoga.

In 2022, a new support was added: a spiritual counselor to help you cope, find connection, and to discover moments of joy and meaning as you and your loved one traverse the many challenges of living with a movement disorder. Patients and their care-partners may feel isolated, self-conscious, fearing the future, and overwhelmed by grief at the loss of their identity.

Building strength in one’s spirit is a valuable aid. Some people with PD have deep religious beliefs that provide strength and meaning, for whom clergy and congregational support can be invaluable. Those who are atheistic or agnostic approach PD challenges with a rational perspective that can benefit from identifying additional meaning and resources. Others are deeply spiritual, without a specific religious affiliation.

What can a spiritual counselor provide to strengthen you and your family through the many challenges these movement disorders place in your life?

The spiritual counselor can accompany you along your journey, providing compassionate listening, useful coping skills, and a non-judgmental presence. She or he can assist you in finding meaning in your current situation and, with open expression of your feelings, facilitate exploration of your challenges and feelings and those of your loved one. For those who are part of a religious tradition, the spiritual counselor can assist your clergy in helping you find a sense of hopefulness, meaning, and self-worth if your physical state makes it difficult for you to travel or participate in-person with your religious community.

Please take advantage of the spiritual counselor’s services at the PDMDC. She or he will help you rediscover your own strengths and meaning.
Reflections of a PALLIATIVE CARE DOCTOR

By Matthew T. Moulakis, MD, PhD

When I first came to Penn in 2013 as an attending physician in neurology and palliative care, I was asked to be part of the COPE (Comprehensive Outpatient Parkinsonism Evaluation) clinic. This interdisciplinary resource offers care from multiple specialists including neurologists, nurses, physical/occupational/speech therapists, social workers, and counselors. Patients and families with atypical or advanced parkinsonian syndromes are invited to the clinic to share experiences, receive support, and learn coping strategies.

It took me some time to figure out what my role would be in joining the COPE clinic, as well as to realize how special that invitation was. Palliative care is still a relative newcomer in neurology, and I was surprised by the message with which I was greeted: “We’ve been waiting for you.” The COPE clinicians at Penn had been seeking a palliative care presence on their team before I arrived, and this was my first indication that they are a special group of people, dedicated to their patients, and ahead of the curve in considering better ways to care for them.

Palliative care at its most basic, and how I introduce it, is “additional support for patients and families facing serious illness.” There are some targeted words here: additional, because it is meant to complement the support already being provided by a patient’s medical team; support, which can take many different forms, from prescribing medication, to giving medical advice, to simply listening; patients and families, since the support is meant to extend to and include all of those close to the patient who are giving care, and serious illness, which may be progressive or chronic, terminal or potentially curable, but which is profoundly affecting the patient’s and their families’ lives.

One of the unique challenges I observe for patients and families affected by movement disorders is how they can come to terms with the clinical nature of their diagnosis. With cancer patients, we can point to scans, biomarkers, and responses to various anti-cancer agents to tell their story. In the COPE clinic, I sit with patients and their caregivers, and we tell each other a story.

Patients and families tell me of months and sometimes years of trying to figure out what was wrong with them. They tell me they sometimes feel lost, not understanding what kind of knowledge will help them navigate the course of their illness and plan for their future. They try to think back to what symptoms might indicate “when this all started,” so that they can count forward, to estimate how much longer they might have to live. They even occasionally tell me they are not convinced they have the kind of illness that their other doctors say they do.

After validating and especially normalizing their concerns, I tell them about the uniqueness of their conditions: that they are incredibly rare, so much so that some physicians may never have seen a patient with their illness; that they are subtler in onset over longer periods of time than diseases like cancer tend to be; and that while they can expect tomorrow will look much like today, next month may hold a different story: one of increased difficulty, less independence, or a frank loss of ability. Finally, I try to give them the sense that unlike scans, blood tests, or other objective measurements, much of what helps them know where they are in the course of their illness is the ongoing relationship they have with their doctors and other care providers.

This relationship is important for anyone with medical illness, of course, but in the case of patients in the COPE clinic, it can sometimes feel like it is all they have. The COPE clinic can help them know that there are many different avenues of care, which can improve their quality of life and their coping.

Advance Care PLANNING

By Lauren Zelouf, MSW, LCSW

I recently heard a social work colleague say “every worry needs a plan.” This is wise advice. Planning for the future can bring comfort to the here and now, because it feels good to know that you have given proper time and attention to looking ahead. It is common for couples living with PD to ask, “what will the future look like for me and my loved one?” Thinking about the future can bring fear and anxiety both to the person with PD and their care partner because of the uncertainty it brings.

One way to ease this anxiety is to have an open dialogue with your loved ones about your values and wishes for the future. This can also give you a sense of control over your life. Some things to consider include the kind and amount of medical care you do or do not want, where you would like to live and receive care as your needs change, and who you want to make decisions on your behalf if you cannot speak for yourself.

Once you have explored and discussed your wishes, it is time to document them in an advance directive. This form includes two components: A Living Will and a Durable Power of Attorney for Health Care. A Living Will is a document that outlines your preferences for how you wish to be treated at the end of life or if you become seriously ill and are unable to communicate. In a Durable Power of Attorney for Health Care, you select those you trust to carry out your wishes as your health-care decision maker(s).

There are many different templates for an advance directive, such as Five Wishes or Penn Medicine’s Our Care Wishes packet created for Penn patients. Both allow you to consider your personal values in terms of what is most important to you: what adds quality to your life and makes life worth living. In order to make the document legal, you must sign it in the presence of two witnesses who are not your appointed health-care decision makers or providers. It is recommended to make several copies for yourself, your family members, and your health-care providers to make sure everyone is on the same page about your care. You may also wish to consult with a lawyer with knowledge of state laws for further guidance.

Having your wishes documented can give you and your family peace of mind for the future.

RESOURCES:

www.fivewishes.org
www.naela.org/findlawyer
The Transmitter interviewed Rich and Cindy Crist who are on the Governor’s Advisory Council of the PDMDC and are also donors for several of our programs.

The Transmitter (TT): Could you tell us a little about your involvement with Penn Medicine and the PDMDC?

Rich and Cindy Crist (R&C): Rich was diagnosed 10 years ago, and was fortunate to become a patient at this amazing Center of Excellence (COE) for PD. The physicians, nurses, physical therapists, and others became our go-to not just for medical care but for support.

TT: Why did you decide to become donors?

R&C: Rich chaired the Muhlenberg College Board of Trustees for nine years, which grew our awareness of the many ways we could help an institution. When we were approached five years ago by the development office at Penn Medicine, we said yes.

TT: What is your experience as donors?

R&C: We try to keep it simple and focused. We were modestly involved in philanthropy for a while, and helped where we could with causes we care about, such as liberal arts, education, and children’s issues. And then, especially after the care we received from Penn, we knew this was our next venture.

R&C: Why did you decide to become donors?

TT: How did you decide the nature of your gifts?

R&C: We felt that the quality of care and level of expertise at the PDMDC were just phenomenal, and we wanted that to be more widely available to others. So, the PDMDC Fellowship Program was a natural fit. We want more providers to be totally dedicated to PD care! I always ask friends who have recently been diagnosed, “are you seen at a Center of Excellence?” Are you with a team that sees large numbers of patients with PD? If not, you need to be.” We are hoping to grow that possibility with the fellowship program.

TT: What else have you been involved with?

R&C: We are excited about a new piece of equipment for physical therapy called the Neofect Smart Balance, which emphasizes core strength and lower body stability to help people practice balance and posture during real-world training scenarios.

TT: What would you say to any potential donor out there?

R&C: We’d say the PDMDC is the place! If we had known ten years ago about how great Rich’s care would be, we would have started then. Our experience at Penn Medicine has convinced us.

Contact Marilyn Touni at 215.341.8223 or mtouni@upenn.edu to learn more about getting involved or to make a gift.

THE PARKINSONS’ DISEASE AND MOVEMENT DISORDERS CENTER (PDMDC)

By Rich and Cindy Crist

THE PARKINSON COUNCIL NEWS

SAVE THE DATE!
“A Shore Event!”
Flip Flop Walk in Avalon
Saturday, July 8, 2023
8:00-10:00 am
Avalon Community Hall

Founded by a family with a personal connection to Parkinson’s, the Flip Flop Walk returns after a two-year hiatus. Family-friendly, hope-driven, and community-focused, FW2023 is the only “shore” event designed with families living with Parkinson’s in mind. Funds raised at this event support 2023 programs and services in the Delaware Valley region, and help The Parkinson Council invest local dollars back into our community for research, comprehensive care, movement programs, and quality-of-life initiatives. Email info@theparkinsoncouncil.org for more information.

Talk the Talk
Date/Location to be determined

It’s back! The Parkinson Council will host a panel of regional experts in Parkinson’s care, innovative scientific and clinical research, and quality of life (art, music, and dance) programs at “Talk the Talk” in the Fall of 2023. Panelists will also include a person living with PD and a care partner to share their story on the importance of a team approach to living well with PD. For more information, contact Wendy Lewis at info@theparkinsoncouncil.org.

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