WHAT MATTERS MOST

Helping individuals and families live well through serious illness is the goal of palliative care. Care teams from the UPMC Palliative and Supportive Institute provide expert symptom management, emotional support, and guidance to help make each step of the journey easier. This is supported by ongoing research and teaching at the University of Pittsburgh.

In This Together

Palliative care offers support to people with serious, life-altering illnesses and their loved ones. Support looks different for each patient and each caregiver depending on specific wants and needs. Palliative care often means jumping into another person's journey and finding where one can help.

"Explaining to the patient and caregiver that we are a team is one of my first steps," says Courtney Wagner, MD, palliative care physician, UPMC. "One of the best ways I can help, especially in that first appointment, is to get to know the patient and caregiver on a personal level. We also discuss their illness and how it has impacted them.

"My goal is to build trust and connection."

Currently, Dr. Wagner is doing so with Mary and her husband, who receive palliative care services through UPMC.

"When my husband's primary care doctor recommended we engage the services of palliative care, we were hesitant at first because we still wanted to keep our primary care doctor and other specialists," Mary says. "But we learned we were able to do so and still add the palliative care team as part of our support system."

Mary and her husband lived with his diagnosis of Parkinson's disease for years before coming to palliative care. Many times, patients come to palliative care at various stages of understanding their illness. Talking through the progression of illness and the potential choices to be made along the way is an important aspect of palliative care.

For Mary and her husband, visits with the palliative care team are setting the stage for trust and communication.

"My husband and I disagree on many topics, but I am his voice now and I want to communicate his wants and his desires," Mary says. "We know it's about the quality of life, not the quantity.

"So, when I can offer him options to choose from what we watch on television or where we go on our walks, I do it because, frankly, it's important for him to be able to make choices wherever he can."

Mary and her husband will continue to make choices based on quality of life. For right now, that means planning trips, taking daily walks, and strengthening connections with the palliative care team.

What Is the Palliative Research Center (PaRC)?

The purpose of palliative care is to help patients with serious illness live better. Palliative care patients at the UPMC Palliative and Supportive Institute benefit from the efforts of the Section of Palliative Care's researchers, who are affiliated with the **Palliative Research Center (PaRC) at the University of Pittsburgh**.

Clinicians from a variety of fields serve important roles in the palliative care team. Because of that, PaRC welcomes researchers from across the health sciences, including public health, nursing, geriatrics, pediatrics, critical care, and more.

Studies conducted at PaRC have made important contributions to:

- Improving clinician-patient communication.
- Understanding when advance care planning is beneficial.
- Developing new methods to manage pain.
- Developing wearable medical tracking devices for the management of uncomfortable symptoms that may accompany illness and the related treatment.

Patients at UPMC's academic hospitals receive cutting-edge interventions from clinical staff who are privy to the latest developments in medical science.

Learn more

The Concurrent Care Program

In April, Dialysis Clinic, Inc. (DCI) held an event in Pittsburgh for attendees to learn more about an innovative concurrent hospice and dialysis program from the clinical team that made it all happen: DCI, palliative care at UPMC, and Family Hospice, part of UPMC.

That same team continues to steward what is known as the Concurrent Care Program and to advocate on behalf of those in need.

Many dialysis patients approaching the end of life must choose between stopping life-sustaining dialysis and starting hospice. To ease the transition between dialysis and hospice, DCI began offering concurrent hospice and dialysis care in collaboration with its clinical partners beginning in 2018.

The April educational event hosted more than 40 people who learned about this unique program and its impact on both the clinicians involved and the family members who have experienced it.

Making concurrent palliative dialysis and hospice care more broadly accessible requires policy change. The recently introduced **Concurrent Care for Comfort Act (H.R. 8376)** , led by U.S. Reps. Mike Kelly and Suzan DelBene, will allow Medicare to cover up to 10 palliative dialysis sessions. This would ease the way for a qualifying patient to benefit from hospice and a dignified death on their own terms.

What does this opportunity mean for affected individuals and family members? Beth Crawford, youngest daughter of Gwendolyn Crawford, explained what it meant for her mother and for her.

Gwendolyn had challenges with managing her diabetes. When she received the news of needing life sustaining dialysis treatment, she was a temporary resident in a nursing home.

Initially, Beth did not think she could provide her mother with the care she needed at home. However, with support from Jane Schell, MD, and the dedicated professionals of DCI and the Concurrent Care Program, Beth acquired the resources and knowledge to bring her mother back home and honor her end-of-life desires.

"I found the support needed to get through one of the most challenging times of my life, and I had the privilege of caring for my mother during the last years of her life," Beth says.

She described how Dr. Schell, her team, and the other partnering medical professionals provided her mother with the highest level of care, while allowing her to make difficult decisions concerning her circumstances. This care was rooted in what Beth calls the "Three Cs" — commitment, compassion, and communication — from which her mother and her family all benefited.

"At one of the most challenging times of my life, I found joy," Beth says. "That joy came through the team of angels that assisted with the care of my wonderful mother during her final years, months, days, and minutes of her life.

"The support during and after her transition has been priceless," Beth adds. "Every family in crisis should have a support system like this."

The Power of the Paw

Tammy Brinker, FNP-BC, is an advanced practice provider with the UPMC Palliative and Supportive Institute (PSI). She works primarily with the patients and families of the UPMC Heart and Vascular Institute (HVI) outpatient clinic at UPMC Presbyterian. Tammy also supports the Benedum Geriatric Center and the Kidney Clinic.

About twice a month, Tammy augments her clinical responsibilities by serving as a pet therapy volunteer in the company of Lucy, her 4-year-old Labrador Retriever.

In the span of a two-hour visit at UPMC Presbyterian, Lucy offers her special energy as replenishment for patients, caregivers, and staff alike.

"Oftentimes, Lucy is a bridge to conversation, to reminiscence, and to home for those who may be missing their own pets," Tammy says. "She can provide motivation for recovery."

Equipped with her own ID badge, bandana, vest, business card, and Instagram account (Therapy_Dog_Lucy), Lucy is quite the pup about town. In addition to visiting the hospital, Lucy visits Family Hospice, part of UPMC; local nursing homes; Allegheny County's 911 center; and even Pittsburgh International Airport.

"Lucy is a testament to the power of a minute of distraction. What a difference it makes," Tammy says. "She instills so much joy."

Humanism in Medicine: Rock and Scroll

In May, the Section of Palliative Care, ***The Canary***, the University of Pittsburgh School of Medicine's MusiCare student group, and the University of Pittsburgh **Institute of Bioethics** came together for a night of music and culture.

The "Humanism in Medicine" event provided an opportunity for performers, including faculty, students, clinical staff, family members of patients and the community, to come together around shared interests in music, poetry and creative writing, and the visual arts. PittMed students Alexander Rothstein and Eugene Kim served as both performers and hosts.

Performances included classical duets and folk songs, songs composed by students, and music from the Beatles. Creative writing originally published in *The Canary* was presented by the authors and included reflections on the experience of being a mother and a caregiver in a rehab facility.

At intermission, performers and audience members connected over food and friendship. The atmosphere was conducive to enjoying a shared passion for the arts as equals.