



Parkinson's Foundation Palliative Care Newsletter

May 2023





Palliative Care Project Updates

- **Access to “Team-Based Palliative Care Essentials” Course in New Learning Management System**
 - As a reminder, access to the palliative care education course titled “Team-based Palliative Care Essentials for Parkinson’s” is available in the learning management system, The Learning Lab. As you know, this course covers the core components of palliative care and how to integrate PC into existing frameworks of care. The course is accredited for physicians, physician assistants, nurses, and social workers (11.00 CME/CE). You can register and access the course [here](#). The course will now live indefinitely in the Parkinson’s Foundation Learning Lab, and you can register for the course to continue accessing the content.
- **Parkinson’s Foundation Presents Findings on Depression, Genetics, and Palliative Care at Annual Neurology Meeting**
 - More than 10,000 neurology professionals gathered to learn the latest in research and treatments at this year’s American Academy of Neurology (AAN) Annual Meeting in Boston. At the event, the Parkinson’s Foundation and the University of Rochester team presented a poster on the availability of resources and current practices among physicians in addressing palliative care needs in their clinics across the 33 US participating Parkinson’s Foundation Centers of Excellence. Access the palliative care poster [here](#) and also read an overview of the findings from two other studies on depression and genetics.
- **Upcoming Palliative Care Town Hall on Hospice & Palliative Care**
 - Our next town hall will be on **Wednesday, June 7th 1-2pm ET** on *Collaboration and Support with Hospice & Palliative Care*. This event will be led by Christina Vaughan, MD, University of Colorado and will include additional speakers from COEs. Please forward the invite to other team members on your team! Zoom link: <https://parkinson.zoom.us/j/83783507246>

Palliative Care Resources & Tips

- **Understanding and Managing Pain in PD**
 - More than 80 percent of people with PD report experiencing pain and many say it’s their most troubling non-motor symptom. Help your patients and families learn more about physical pain in Parkinson’s disease, including why it happens, tools to manage pain, and the importance of movement during the **Parkinson’s Foundation’s Midwest Chapter Symposium**. This event will take place on **June 3rd, 2023 at 1:00 - 4:00 pm CDT**. Interested participants can register for the event [here](#).
- **Podcast Episode: Dispelling Myths of Palliative Care**
 - A common misconception is that palliative care implies hospice, when in fact, palliative care should be a component of the treatment of any serious disease, including Parkinson’s. In this podcast episode, Maggie Ivancic, MSW, LCSW, University of North Carolina – Chapel Hill, discusses what palliative care is, where to access it, and how it differs from hospice. Listen to the full episode [here](#).
- **Survey from the University of Colorado**

The University of Colorado team recently developed a survey for people with Parkinson’s and their care partners to assess quality of life, spiritual distress, and care partner burden. In addition, it asks about additional needs regarding advance care planning and if a conversation is needed. You can access the survey [here](#). Passcode UqKS3oKC.

The Art Therapy in Neuroscience and Medicine at Indiana University

By Ashley Hildebrandt, M.A., ATR-BC, and Julie King, PhDc, ATR-BC, LPC, LMHC



Tulips

Permanent installation, Indiana University Health Neuroscience Center, Indianapolis, IN

Participant comment: *“Each session gave me the ‘permission’ so to speak, to relax, and calm my mind for two hours and concentrate on nothing but art which usually helped calm my tremors and anxiety related to Parkinson's. I have a renewed interest in art making due to this program and truly appreciate the therapists and the artists that have become a part of my Parkinson's therapy team.”*

The Art Therapy in Neuroscience and Medicine (ATNM) program was initiated at Indiana University Health Neuroscience Center in 2015. The program offers clinical art therapy services for patients with neurological conditions including Parkinson's Disease and also supportive interventions for caregivers. Trained also in “talk therapy (e.g., traditional psychotherapy), art therapists use the creative process, materials, and methods to foster patient goals across a range of populations. Art therapy is defined by the American Art Therapy Association as “a mental health profession that enriches the lives of individuals, families, and communities through active art-making, creative process, applied psychological theory, and human experience within a psychotherapeutic relationship.” (AATA, 2021).

ATNM was awarded a Parkinson's Foundation Community Grant in 2019 to develop a virtual creative arts therapies programming for people with PD, in an effort to reduce social isolation and address nonmotor symptoms during the global pandemic. Art therapy has shown to be valuable as a virtual intervention through telehealth efforts. In our program, 12 people with PD, in varying stages of the disease and located throughout Indiana, met weekly over Zoom for three months to create the mural Tulips. The success of this program has led to ongoing virtual art therapy group programming for people with PD and their care partners. Participants have reported the following benefits of art therapy: opportunities for peer support and community-building, improved self-expression, relaxation, reduced anxiety and tremors, positive impact on self-esteem, and an activity to look forward to each week. These outcomes have been supported with evidence-based research across patient populations. Our hope is to continue providing clinical services and build research to support art therapy in the treatment of a range of neurological conditions.

If you have any questions about palliative care implementation at your center, including any challenges or barriers that your center has encountered, please submit them to Jinnia Nusrat at jnusrat@parkinson.org to be answered in a future edition.



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Palliative Care Implementation at Augusta University Medical Center

By Julie Kurek, M.D., Medical Director, Palliative Care Champion, Augusta University Medical Center

We reached out and asked Julie Kurek, MD to reflect on the changes and achievements the Augusta University Medical Center COE has experienced integrating palliative care thus far. You can read the thoughtful reflections below.

Relationship- this is the word that keeps coming to mind reflecting on the changes we have seen at our center over the course of the Palliative Care Project. We strengthened existing ones, forged new ones both at our medical campus and within the community at large, and effectively expanded our “village” and toolbox of resources.

COVID-19 changed so many landscapes, including the medical one bringing both challenges and opportunities. In the face of financial constraints and job turnover, necessity indeed became the mother of invention. We launched our first ever social work internship allowing a student to gain invaluable clinical experience and in turn providing us with the much-needed support to advance our projects.

To strengthen our team and foster collaborative discussions about palliative care, we initiated frequent in-person meetings, which brought us closer and gave us a renewed sense of purpose. It was a significant change from the more isolated work during the challenging times of COVID-19.

At the start of the PF Palliative Care Project, Augusta University did not have a Palliative Care division. When talks were underway to recruit a division leader, we were able to get involved from the ground up from the interview process to quick collaboration once the division was in fact established at our Cancer Center. We were able to engage in mutually beneficial education, learning about palliative care and Parkinson's respectively through Grand Rounds, the wonderful PF course materials and so on. Together we created the first outpatient palliative care clinic for our Parkinson's patients and our COE will become the Palliative Care Model for the neurology department as a whole.

The project brought chaplaincy to the outpatient neurology department for the first time. No longer did we view them as an inpatient division for “last rites” but rather a source of support not only for the patients and their families but as an unexpected bonus for the staff themselves. Annually, our chaplains participate in a “blessing of the hands” ceremony during nurses' week. Because of our relationship forged through the project, our chaplain made a special point to meet with our team emphasizing that he was OUR chaplain too. This thoughtful gesture served as a deposit in the fight against burnout and compassion fatigue. While modern healthcare practices can leave some feeling morally injured, we saw moral repair.

We have had transformative experiences highlighting the power of interdisciplinary care which have reinvigorated our appreciation for it. One of the most beautiful moments for me in this project thus far was an ad hoc Palliative Care Clinic. It was our very first one with the plan for an official start 2 months later. However, in light of multiple emergency room visits we knew we had to work quickly. We faced a 43-year-old woman with rapidly advancing parkinsonism, deep denial, and an overwhelmed father. Isolated visits with myself and our neuropsychologist were modestly productive.

When we sat as a team- neurologist, nurse, social worker and chaplain- together with the patient and her family, we achieved something we weren't able to do alone. As the patient began throwing out protests and questions like weapons to distract her from the ugly elephant in the room, a team member was able to field each one, eventually leaving her with nothing left to ask, but to sit there and face the difficult truth at hand. It was a breakdown and a breakthrough. There was sobbing, long painful silences, yet it was also one of the most beautiful things I have ever witnessed in my years of practice.

The analogy that came to mind was a fine-tuned orchestra resulting in this “music” that was able to reach her spirit. It felt like we were making true fundamental change, not peripheral “tweaking.” Independently, we all talked about how moving the experience was.



Speaking of orchestra, the framework and platform of the Palliative Care Project allowed many independent and moving pieces to come together for our center. Our neurology department recently bought down time from the Psychiatry/Psychology department as in many places the need for such care is great and the resources scarce. Working together to leverage access, we plan on moving forward with group Supportive Care return visits with the neuropsychologist for the patients and separately for their care partners. Given telehealth options that strengthened with covid, we are considering hybrid models with in-person and telehealth options.

More than anything, this project gave us the opportunity to sit back and reflect on how we might do things differently, extend our capacity and truly meet the needs of our Parkinson's patients. A senior colleague once said "Parkinson's patients don't die. They just stop coming to clinic." This cheeky quote captures with some humor the sad reality of the gap found at the end of life.

Now we had ways to address this head on and at the very least feel more comfortable conducting the conversations regarding this anticipated period in life. We were pleasantly surprised that many local hospice agencies were willing to work with us and allow us to remain on the care team, as the main roadblock for many patients was the fear of being cut off from us. Our nurse and social worker met with local hospices to identify those that had some understanding of movement disorders and would be willing to include our neurologist/movement specialist in the continued care of our patients while on hospice – to include PD medication management. As we move forward, our social worker and/or nurse will maintain contact with the patient, family, and the hospice nurse/social worker to ensure that our patient and care partner's needs are met.

Over the years we have built a strong community presence through educational and community outreach programs. The Palliative Care Project has strengthened bridges and created new relationships with the greater healthcare community resulting in more educational events related to advanced care planning covering logistics from medical to legal and financial with lawyers and agencies volunteering their time. Speaking on Palliative Care at our annual symposium, we saw how hungry people were for knowledge and education on the subject. It has been eye opening and educational for us as well as we are often isolated from those practicalities that are important determinants of a person's quality of life, especially towards the end.

In terms of practical logistics, The PF Coaching meetings were invaluable. An implementation plan was designed with tasks, ownership, status, and completion dates to keep things moving and on target. All members of the team were included in determining prescreening forms to be used. From the onset the greater team included neurologist, social worker, nurse, chaplain, psychologist, psychiatrist, oncology palliative care physician. For our first clinic, we decided to include a set of patients plus care partner(s) at both early stage and late-stage PD. Our goal was to challenge the team with the gamut of issues patients and their care partners experience at the different ends of the spectrum and thus be more prepared for future clinics.

Patients were given prescreen forms to complete prior to the visit with the choice to complete via email or in person. Additionally, the nurse and social worker contacted patients prior to the visit to further expand on what they could expect at the visit. The completed pre-screen forms along with a synopsis of each patient was shared with each team member prior to meeting with the patient and care partner(s) so we could focus on the issues most vital to the patient. The preliminary preparation was key in having any necessary materials on hand such as advanced directive or MOLST form.

We are still in the process of figuring out our flow, finding the best ways to complement each other while avoiding redundancy. Sustainability and reach are issues we continue to consider. Undoubtedly there is comfort in going through this process together as not one person has to "do it all."

Over the three years of the project there were many online searches, emails, one-on-one conversations, meetings, moving pieces, stops- and- starts. Just as a relationship was set up, said person left or some factor changed. I include this to serve as encouragement to others who may be or have faced similar struggles. With time and persistence, our efforts thankfully coalesced to our current set-up. And what has been most encouraging is the goodwill of others recognizing the importance and necessity for this effort, volunteering their time, skills and resources to bring the parts together and off the ground. It truly does take a village.