



Parkinson's Foundation Palliative Care Champion Newsletter

September 2022





Palliative Care Project Updates

1. PC Education Course Update

- Thank you for your patience as we transition the course to our new learning platform and accredit the course through the Parkinson's Foundation. Our goal is to re-launch the course soon in **October 2022**. We will follow-up with additional details on accessing the course and platform shortly.

2. MDS International Congress 2022

- A few members of the Clinical Affairs team at the Parkinson's Foundation attended the 2022 International Congress of Parkinson's Disease and Movement Disorders in Madrid, Spain. A poster on the study design of the palliative care implementation project was presented by Megan Dini. The poster was well received and sparked a lot of enthusiasm and interest from many international attendees. You can see the poster [here](#).

3. Upcoming Palliative Care Champion Focus Groups

- Starting November, Palliative Care Champions will be invited to share their ideas and thoughts on the project. Each Focus Group will be for approximately 1 hour in duration and will be an opportunity to share your perceptions of the successes and challenges associated with the implementation, plans for sustainment, and your role as a champion. We received positive feedback from champions who participated in our initial focus groups (referenced in Grace Crotty's section below), and we hope they will continue to serve as an excellent learning opportunity for all participants. We will be reaching out and providing more information soon.

Palliative Care Resources & Tips

• Egnyte (File Sharing Resource for COEs)

- The Palliative Care Champion Newsletters will be uploaded to Egnyte in the PC Champion Newsletter folder located under Project Resources. You can also access your meeting notes and additional resources in Egnyte. Please contact Jinnia Nusrat if you need assistance accessing your Egnyte account. You can log-in to your Egnyte account [here](#).

• Aggression Towards Caregivers in Parkinson's Disease and Related Disorders: A Mixed Methods Study

- A recent publication in Movement Disorders Clinical Practice Journal describes characteristics, associated factors, and consequences of aggression towards caregivers in PDRD. This mixed-methods study highlights not only the diverse factors, such as grief and fluctuations in cognition that result in aggression but also serious consequences for caregivers. Access the article [here](#).

• C-TAC Advisor Interviewed by Hospice News on a Standardized Definition for Palliative Care – The Coalition to Transform Advanced Care

- The Coalition to Transform Advanced Care (C-TAC) recently facilitated discussions between CMMI, health plans and other private payers on ways to integrate palliative care services into existing payment models. Read the full article [here](#).



Center Spotlight: Palliative Care COE Implementation

New Review of Systems Form at the University of Rochester

Karlo Lizarraga, M.D., M.Sc., Chief, Division of Movement Disorders, University of Rochester

Dr. Lizarraga, Palliative Care Champions Dr. Blanca Valdovinos and Aida Santiago, NP, and the rest of the team at the University of Rochester recently developed and launched a new Review of Systems (ROS) form. We asked Dr. Lizarraga some questions below about the new form and process.

1. What prompted you to create a new ROS? Our care team received feedback from patients and their care-partners about the questionnaire forms given to them when checking in for appointments. These forms had been created several years ago mainly to comply with documentation requirements. They were several pages long and they were difficult for patients to read and complete while waiting to see their provider. Moreover, providers did not find the forms useful for the appointments themselves. Our team saw the opportunity to update the forms when the need to document a review of systems was removed in early 2021.

2. Which members of your team worked on this? Everybody contributed during division meetings, via email or quick face-to-face chats.

3. How did you decide on what to include in the ROS form? First, we took some time to understand the historical background leading to the multiple versions of the forms. We then reconciled all versions and made sure we were using non-technical language. We reviewed this unified version, reconciled with patient feedback and division priorities, and defined consensus goals for an updated version. Our main goal was to update the form so that it would help prioritize problems to address during appointments. Other goals were to integrate quality measures, palliative care efforts, community outreach and study recruitment efforts.

4. Are there any new elements on the form that you think are specifically important? In the first two pages, we simplified the prior form in a table format that organizes potential problems by their perceived frequency during the last month. Page 3 includes the new elements. First, patients and carepartners prioritize three problems that they would like to discuss. This is followed by “yes/no” questions and a checklist that address quality measures (recently published by the American Academy of Neurology), palliative care pillars and other division priorities. Patients and carepartners are then able to write any other issue not mentioned that they would like to discuss. We have seen “thank you” in this line several times already.

5. What challenges did you encounter when developing a new ROS form? The main challenge for us was to harmonize and create consensus to move our team efforts forward based on potentially conflicting feedback.

6. What are your next steps for implementing this new system? We are moving towards creating an electronic version of this form to be available in our electronic record system. Patients and carepartners could fill out this version ahead of their clinic appointments if they prefer to do so. This electronic version could also help providers with documentation and be better prepared to address prioritized problems ahead of time.

7. Any suggestions or tips on successfully creating and implementing new systems such as your ROS? A team-based approach with enough time to go through the process of quality improvement together.

You can access the University of Rochester ROS form in the Egnyte resource folder [here](#).



Tips for Engaging the Team in the PC Education Course from Massachusetts General Hospital

Grace Crotty, MD, Palliative Care Champion, Massachusetts General Hospital (MGH)

Grace Crotty, MD and her team at MGH were able to engage all of their providers in the palliative care education course, with 21 providers completing the full palliative care course. We asked her some questions on what led to the success of their center and how she was able to obtain provider buy-in. Here is what she said:

At Massachusetts General Hospital, we have 21 providers caring for individuals with Parkinson's disease. Initially, the thought of ensuring all providers completed the educational course was daunting. However, our center ended up engaging with the course with excellent provider buy-in, and many providers completed it within the first few months of its roll-out. At our center, we decided collectively that each provider would complete the course individually with internal deadlines to complete certain modules.

As the palliative care champion, my main responsibilities for this education course were to ensure that providers were engaging with it throughout the year and to be available for any concerns or problems that arose from it. To fulfill these responsibilities, every month during our movement disorders division meeting, I spent ten minutes reminding our providers of the Parkinson's Foundation PCORI Palliative care project, re-educating them on why the education course is important to our patients, our center, and us, and providing a status update on the percentage of providers who have completed the course. Following these meetings, I sent an email recapping this information and providing reminders on our internal deadlines for course completion.

Key to the success at our center was the following: 1) Support from our center's leadership. 2) Regular reminders of internal deadlines at our monthly division meetings and afterward via email. 3) Learning from other centers' palliative care champions at the Palliative Care Focus Group at the Parkinson's Foundation Centers of Excellence Leadership Conference (CLC).

Question and Answer:

Question: I am wondering how to handle documenting caregiver issues in the chart...particularly if there are sensitive issues or concerns that the patient may look at their notes?

"We have an option to not make a chart note visible to the patient. An explanation must be given for choosing that option. I use this option when documenting a conversation with a caregiver that might be inappropriate to share. I also write shorter caregiver notes and leave out details that do not need to be in the formal record. For example, I might write, "Explored Mrs. Jones' anger and frustration" rather than going into detail about what incident(s) was discussed." - Sue Ouellette, PhD, M.Div.

"It is OK in general to reference the carepartner in the chart in their role as caregiver. This is different than treating them as a patient. For example, in your history: "Nancy, John's wife and primary caregiver, is struggling with keeping up with tasks at home and reports some burn-out." Or in your Plan: "1. Caregiver Burnout: We will work with our social work colleagues to provide information on aid services and caregiver wellbeing with the goal of giving Nancy some time during the week for self-care." - Benzi Kluger, MD

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.