

Camilla's discussion about PSP and Palliative Care

Local support group member Camilla recently spoke to the Palo Alto senior community where she lives about corticobasal degeneration (CBD) and palliative care. CBD is a very rare disorder. It is sometimes called an atypical parkinsonism disorder. Palliative care is little-understood field of medicine that focuses on comfort and the whole person. These are notes Camilla shared of her remarks.

Excerpts from "Discussion about Palliative Care"

Speaker: Camilla Olson (resident)

At the Vi, Palo Alto

November 20, 2023

Remarks by Camilla Olson

Faced with a difficult diagnosis, Camilla needed to make a big course correction to live a meaningful life.

2.5 years ago she was in NY and experienced 45 minutes of total amnesia. She went to MD. An excessive amount of tau protein was found in her brain.

Diagnosis: Corticobasal degeneration. Online description: a rare condition in which areas of your brain shrink and your nerve cells degenerate and die over time. The disease affects the area of the brain that processes information and brain structures that control movement. It may also cause problems with memory and thinking. This syndrome is distinct from Parkinson's disease in regards to other clinical features and its response to treatment. It typically has a 5-7 year course.

Camilla's message: Each of us is special; we each have our own story, and figure out how we want to live our lives.

Her relationship with palliative care (PC) and specifics on how she has dealt with her diagnosis

Living at the Vi has improved her situation considerably. Unexpectedly, her disease has stabilized and is not progressing as expected. She is eating better food; has lost 10 pounds, and has positive social interactions. She loves puzzles and art, and being involved in these activities are good for her. She is religious about exercising regularly, including swimming twice a week, working out with a trainer in the Fitness Center, and taking daily walks.

Camilla has been very open about her situation, which relieves some of her stress. She and her husband worked with a couples counselor who advised them as they made their decision to move to Vi. Health psychologists can help people who are dealing with health care challenges. Camilla has also consulted with the Resident Services Director and with the Director of Social Services.

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She has a team of 20+ doctors and therapists at Stanford, and also works with a therapist at Orange County Health Psychologists Group in Irvine.

Camilla became part of the UCSF Memory and Aging Center Program Project Grant protocol in February 2023. The conclusion in the UCSF Year-1 evaluation concurred with the Stanford diagnosis.

Camilla's situation has caused her to think carefully about the Advance Directive and POLST forms. It's all very personal and is typically different for each individual. Her medical condition means that she will lose the ability to communicate. Completing the AD and POLST forms led her to Palliative Care. She is early in the course of the disease and currently meets quarterly with the team. There have been 3 meetings since March 20, 2023. This schedule will continue until her condition changes. Camilla sees her primary care physician, who is not affiliated with Stanford every 6 weeks. She also confers with her neurologist 2-3 times a year.

Description of palliative care team meetings

- The care team who attended the first meeting with Camilla included an MD, a member of the clergy, and a social worker. The meetings are on the phone for an hour. After the call, each participant writes a detailed report, covering Camilla's living situation, mental health, caregiver, goals, social history, and physical appearance.

The reverend discussed Camilla's faith background, spiritual choices, making decisions, values, a spiritual care plan, and her fears. The social worker addressed Camilla's home, friends, supports, financial resources, bereavement, fears and worries.

- The second meeting took place 3 months later, with only Dr. Ramchandran (Stanford palliative care physician) and her scribe. With Camilla's permission, Dr. Ramchandran had conferred with Camilla's neurologist. Both agreed that it's too soon for prescription medication to end life. Camilla was assured that the team will look for evidence of dementia and/or loss of the ability to swallow. They will watch for her—she doesn't have to worry about these concerns.

- Meeting 3: The UCSF study had ended. The group had a detailed discussion of Camilla's mobility, mood, sleep quality, physical assessment, and Advance Directive. The next meeting will be in mid-December.

Read more-questions for Camilla here-<https://www.brainsupportnetwork.org/local-group-member-camilla-on-cbd-palliative-care/>