

## Pearls and Chocolate Brownies

*by Loy Campbell, MS, OTR/L  
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Think about your favorite food in the world. If calories were no object, what would you eat every day? For me, it's a double chocolate brownie (with chocolate fudge melted on top). Now imagine, if you can, that you are living as a Pearl (or what the non-Positive Approach® to Care (PAC) world would call "end stage dementia"). You require assistance to complete all daily activities, including eating. Fortunately, you have a care partner who has PAC skills and is assisting you using Hand-under-Hand® (HuH®) to eat your favorite food. A new advance directive in New York was developed allowing a person without dementia to determine for their future self, if they were to develop dementia, what their choices would be. This advance directive would determine what to do in the event they are unable to feed themselves, and form words explaining their choices regarding whether or not to feed them. The options for their Healthcare Power of Attorney to honor are 1. NO food or fluid assistance by hand (even if I seem to want it), versus 2. just provide food for pleasure and help me with eating, but do not force me if I am not appearing to enjoy it. (For more details, [click here](#))

As an occupational therapist working with PAC and in hospice and acute care settings, I am a big proponent of advance directives. They help patients to avoid unnecessary pain and suffering, help families to reduce arguments and guilt, help medical establishments prevent fruitless medical spending, and make it possible to honor the wishes of a person who can no longer speak for themselves. I am also a big proponent of palliative medicine: approaching terminal illnesses such as diseases that cause dementia with a focus on comfort over quantity of life. Given our cultural perception of Pearls (I won't list them, as we all know the stereotypes), I can see how a document that allows us the choice of opting-out of Pearl state would be appealing. There are many real challenges to living well as a Pearl. It is tempting to approach this new "Advance Directive for Receiving Food and Fluid in Dementia" around the question of whether, in theory, life as a Pearl is worth living.

But I think the actual question we should be asking is this: Can Pearls communicate their likes, wants, and needs? At its core, this new advance directive strikes me as a misunderstanding of the communication skills of Pearls. Unlike other advance directives that provide guidance to healthcare providers and families about what to do in the event that I am incapacitated and unable to communicate in any way, this new advance directive allows me [as a fully functioning adult] telling a future me [as a person with dementia but still very much alive and able to respond consciously to stimuli] what I want. Diseases causing dementia generally allow retention of interaction and communication, even if not in words and sentences the way our society prefers. In Hand-under-Hand® position, a skilled care partner can receive feedback from a Pearl physically (with a pushback on the care partner's hand), verbally (with sounds indicating dislike), and visually (with grimaces or head shaking). This gives me a pretty good idea that either the person isn't liking the

food I'm providing, or the person is done eating - perhaps for now or perhaps forever. Just as in other [GEMS®](#) states, people living with dementia are constantly communicating with us through actions; we must have the skills to understand what they are trying to tell us. Therefore, I find it odd that we have an advance directive for Pearls when it comes to communicating preferences about eating; unlike people in other situations where advance directives come into play, Pearls can communicate their preference to eat or not to eat.

As for me, I'd rather have skilled care partners around to help determine what I am communicating in my Pearl state, rather than potentially regretting the choice of my younger self that my life as a Pearl is not worth living. In cruel irony, I would have no way of communicating in the formal legal way that documents such as these require in order to tell my care partners that I do want that double chocolate brownie. While I have no moral qualm with such an advance directive existing - in the end, if I made a different choice, it would be me living with my choice - I fear that, because of cultural devaluation of the lives of Pearls and unawareness of the ability of Pearls to communicate, others may end up making a choice that they will later regret when their Pearl moment arrives.

*Loy is an occupational therapist working with people living with dementia and their families in several settings. With Positive Approach to Care, Loy consults with families and professionals who are facing challenging care situations, travels the country leading [PAC trainings](#), and mentors learners in [PAC certification programs](#). In her other occupational therapy roles, she makes home visits for Hospice of Alamance-Caswell (Burlington, NC) in their home health and hospice programs, as well as working with patients in acute care and inpatient rehabilitation at Duke Regional Hospital (Durham, NC).*

*Prior to becoming an occupational therapist, Loy earned a bachelor's degree in sociology from the University of Mary Washington (Virginia). She then spent three years in Northern California working at an assisted living facility; it was there that she found her passion for care partnering with people living with dementia. Her job was focused on facilitating individualized meaningful activities with each resident of the building's dementia care neighborhood. She earned a master's degree in Occupational Therapy from San Jose State University. In her free time, Loy enjoys playing tennis, quilting, reading nonfiction, traveling, and weekend trips to her hometown of Blacksburg, Virginia, to visit family and watch Hokie football.*

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['Aggressive' New Advance Directive Would Let Dementia Patients Refuse Food About the Advance Directive for Receiving Oral Food and Fluids in Dementia End of Life Care & Letting Go](#)