

Apparently, this is a fairly HOT TOPIC in the world of dementia!

In October, I provided webinars and several workshop sessions on the topic of sexuality and intimacy issues as they relate to dementia. People are interested, and yet, there continues to be a huge gap between what we understand about dementia and changes that accompany that condition and our personal reactions and opinions, our educational efforts, our person-centered care plans, and our social, regulatory, and legal support systems.

In this piece, I want to spend a little more time trying to explore the double messages and inequalities that are inherent in our current way of providing support and care for people who are living with dementia and their intimates.

Human beings come to have relationships with others over time. Yes, it is certainly possible to be drawn to another person, place, animal, sensation, or object immediately. However, it is only after exposure for a period of time that the person can determine how much, how often, how long, and how close the **other** should be to provide the **just right** fit and experience in my intimate space and life. It takes time and exposure to figure out when being that intense, that frequent, that long, or that close becomes uncomfortable, unpleasant, unwanted, and finally needing it to stop or to have a break. When the **other** is an object, place, or sensation, it is easy enough for most people to simply move away from the sensation and take a break. If the **other** is an animal, there are expectations that the person must find someone else to care for the animal while they are gone or the animal should have its needs met in some fashion while the person is away, hence pet sitters, kennels, companion animals, pet toys, and day care centers. When it comes to the **other** being another person, things can get messy. There are now two individuals with separate sets of likes, wants, and needs related to the **other** and both will be seeking the just right match, however one person's brain is changing without their permission.

I would pose several questions to get us to consider more carefully what we choose to do and how we do it, related to helping someone cope with having changes in intimates.

1. How thoughtful and careful are we in establishing our relationship with the PLwD and their existing intimates?

Do we begin as someone unknown to the person, and then get permission to become acquainted? Do we then seek permission to become a friend? And only then seek permission to become intimate enough to ask personal questions about likes/dislikes, wants/don't wants, and needs to/needs to not, and expect honest answers? And finally, do we recognize the value of getting permission to offer caring care and intimate touch during self-care and life care tasks each time we

want to help, so that our intentions are clear and our offer is accepted in the way we meant it to be interpreted. What sensory processing systems do we use? How do we use them?

2. Are we curious about what and who are the most important **others** in the person's life?

Do we investigate to determine what are some of the most important features and elements of the **other** for that person? Are they places, tasks, objects, animals, or people? How much? When? What are the details that matter? Are those **others** still a match for what the person is now indicating they prefer or don't like as much anymore? Do we try to figure out if the person simply needs a change in timing, frequency, intensity, or location in order to find the pleasure and joy in the **other** from before?

3. Are we supportive of the person's intimate **other**?

In our effort to help the person living with dementia, we can get so focused on that person that we miss the pain and frustration that the **other** is feeling with the changes and changing abilities. We can make it seem to that **other** as though their person no longer needs them. We can make it seem as though we think we can provide the intimate relationships, support, and care that the person needs, so that individual is no longer needed or even wanted in the mix. Or that no one else could do what the **other** had been doing for that person and less will have to be acceptable to both the person and the other. Instead of using the same curiosity and relationship-building skills we at PAC use with PLwD, we can try to get intimate and very personal information out of the **other** in order for us to take their place in some areas. What we miss, all too frequently, is how that impacts the **other**. If, instead, we employ these same permission seeking/granting processes with those who have been part of the person's life prior to our arrival, we can then build a revised team of **others** to support the person on their journey.

4. Are we creating a team of support that works together?

The older model had us working in silos dependent on task, shift, profession, personal preferences and beliefs, or a set of organizational or governmental rules that were not designed to address the life of a person living with dementia and their caregivers. Unfortunately, many regulations and guidelines still exist that are outdated and built on questionable data and beliefs about people living with dementia. There is much that has changed in our understanding of who these individuals are and what they are able to think, do, and say throughout the course of their progression through their particular dementia or dementias. Very little of this new awareness has been translated into health care curricula, legal support curricula, social services training, or support service provision in a meaningful or coherent way.

5. What happens when the person is no longer able to move toward or away from the **other**?

In later GEMS States, we acknowledge that the person's control over their mobility system, sensory processing systems, and communication systems is significantly altered. Are we consistently using our skilled observations and abilities to interpret what the person is trying to share out about what is liked/disliked, wanted/not wanted, need to/need not to? Or are we using what has been noted from before, our previous interaction, the notes in the chart, the report of the family to judge the person, and what might be happening for that person in that moment of time?

Rather than labeling the person as resistive, uncooperative, agitated, or aggressive, perhaps we should consider the possibility that the person is missing the **other**, is seeking the **other**, is overwhelmed by the intensity, frequency, or closeness of the **other**, maybe simply never gave permission for the **other** to do what the **other** is doing. And frankly, without some giving of permission, it could be called being resistive, uncooperative, agitated, or aggressive, if you were in **other** person's shoes. Just a possibility to consider.

Who are your intimates? Have you told them what you will want if you ever develop dementia? Advance directives are much more than decisions about how my life will end. They can help us better appreciate how I will want to live and what it means to me to live well with changes in my intimacy needs and the **others** who might provide it.