



May 15, 2020

Greetings!

My name is Felicia Greenfield. I'm the Executive Director of the Penn Memory Center (PMC). I'm writing along with PMC Co-Directors, Jason Karlawish, MD and David Wolk, MD, to share with you insights we've learned from a series of Town Hall meetings with families with a loved one residing in a memory care facility. It is my and my colleagues' hope that these insights will help us all come together to develop strategies to improve the care of persons living with dementia.

The Penn Memory Center is a diagnostic, research and treatment center for people with Alzheimer's disease and related disorders. We support family caregivers over the course of the patient's illness, often up to 10+ years. When families are unable to care for their loved one at home, we work them on the difficult decision to place their loved one in facility care. We make referrals to many memory care facilities.

As a result of COVID-19, we've moved our family services and supports on line. We also added supports. One of those new supports are "Town Hall meetings" where caregivers can voice their concerns and share ideas about how to care for a person living with dementia during these very challenging times created by "social distancing."

During our open caregiver forums, several caregivers shared concerns. We feel compelled to share them with you and hope to work with you to find creative ways to meet the needs of our mutual patients and families. Yes, these concerns have been voiced as a result of the current awful circumstances, but they are relevant to the more "normal" times we all yearn to return to.

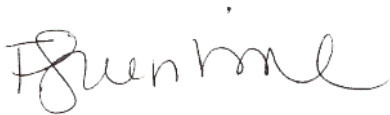
1. Ongoing communication between memory units and families is *really* important. Families are keen to learn about ongoing resident activities, specifically sharing information about how residents are spending their days and, even better, sending pictures or videos. Several participants in the forum also identified the need for a better defined process for connecting residents and family members via FaceTime or similar technologies. Caregivers are also interested in hearing about the following:
 - a. Changes in visitation rules;
 - b. Supply and consistent use of masks and gloves for facility staff - and level of oversight,
 - c. Strategies for screening of staff and residents for fever and other symptoms;
 - d. Updates on newly identified COVID-19 cases and staff and resident screening (while adhering to HIPAA guidelines).
2. Caregivers/family members crave transparency about the policies: were they mandated by state and other government agencies, or corporate offices, or local initiatives? Participants in the forum felt the need for access to such information and how it might apply, for example, to questions such as when residents are sent to emergency rooms or considered too complex or fragile for care in a memory unit.

If there was an **overall, common theme** it was this: The need for timely and substantive communication with facility leadership. Many of the families in our forums emphasized this point and expressed disappointment when they were unable to make contact with the facility leadership to voice concerns about their family member. Facility and unit directors are understandably under a great deal of stress with many complicated decisions to attend to, but clear communication with families can provide considerable comfort in these uncertain times.

The Penn Memory Center is committed to improving the care of persons living with dementia and their families. My colleagues and I would like to work with you on is how to facilitate regular and meaningful communication on these topics. They are important at all times, and now in particular.

Please share this letter with your leadership team. We welcome your feedback and response. I am available at 215-450-7925 or email felicia.greenfield@penmedicine.upenn.edu.

Sincerely,

A handwritten signature in cursive script, appearing to read "F Greenfield".

Felicia Greenfield, MSW, LCSW, Penn Memory Center Executive Director

A handwritten signature in cursive script, appearing to read "J Karlawish".

Jason Karlawish, MD, Penn Memory Center Co-Director

A handwritten signature in cursive script, appearing to read "D Wolk".

David Wolk, MD, Penn Memory Center Co-Director