

**Caring for People Living with Alzheimer's  
PULSE of NY Patient Safety Advisory Council  
March 2016**

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In January 2016, a PULSE of NY Patient Safety Advisory Council (PSAC) representative visited five support groups held at the Alzheimer's Disease Resource Center (ADRC) in Bayshore, Long Island. At these meetings she spoke to caregivers helping people living with Alzheimer's disease. The mission of the ADRC is to support research that may lead to a cure for Alzheimer's disease, to provide care, support and education programs for families in need, and to be advocates for local families who are coping with Alzheimer's disease and other dementias.

The PSAC was developed to reach Long Island's diverse populations and educate them in patient safety. Through a series of meetings and conversations PSAC representatives identify some of the obstacles people face in receiving safe, quality care. Then a report is created, leading to the development of tools to help improve the care.

The participants in these Alzheimer's support meetings were all extremely committed to their loved ones: thus the need for support and information, which is given freely and at no charge by the ADRC staff.

Each meeting was opened with an introduction to PULSE of NY and the concept of patient safety. Then, the participants were encouraged to discuss their experiences and suggest where improvements might be made to help their loved one receive safe, quality medical care.

Many of the group had their loved ones living at home. Determined to keep their family member close by, the caregivers welcomed the support from each other and the sharing of information.

The discussion of medical care triggered responses of frustration for many of the participants. One man spoke about his father who had bedsores, an infection, and the son felt his father was not treated appropriately and with enough urgency. Because his father could not speak for himself, the son grew more frustrated at the lack of urgency in his father's care. His father subsequently died, leading the son to believe that his death was due to lack of medical attention. Other's shared that lack of patient communication about a serious matter was an obstacle.

The importance of early conversations about advance directives was another topic discussed, and all agreed it would be helpful to have that discussion early in the onset of the disease if it has not been done earlier. Waiting too long can be too late.

People living with Alzheimer's and dementia may become easily frustrated and agitated. Each group had stories about being kept waiting to see a clinician and how it affected their family member's behavior and their trust in a clinician who would run late with no explanation under these circumstances. Participants were in agreement that a person with dementia should not be kept waiting in a doctor's office.

- Clinicians might consider dedicating set times for patients with dementia so as to be sure there is no wait. Office staff can be in contact with the families to be sure there won't be unnecessary waiting.

Another reported topic was driving. Once a doctor and the family decide a person should not be driving, there needs to be a more efficient way of taking away the person's driver's license. The process currently takes "too long."

One reported difficulty is that many Alzheimer's sufferers do not display their symptoms all the time; if they seem rational while visiting a doctor, the clinician may not recognize that their clarity is only temporary.

When someone who has Alzheimer's or dementia accompanies a loved one to the hospital in an emergency, he or she needs to be watched carefully. In one case a husband who had dementia was with his wife who was receiving emergency room treatment. Left unattended, the husband wandered off, causing fear and agitation to the patient and a safety issue for the hospital.

Family members who are caring for someone with dementia and may be brought to the hospital in an emergency could be wearing a bracelet or carry that information so in an emergency medical staff knows there may be someone waiting for them at home.

All participants agreed that family should be available and on call for calming a patient who has dementia. They know the patient best and should be involved in all care planning.

Additional suggestions:

- Some people with dementia do not yet know they have it and the family needs to be included in the decision about when they should be told.
- Medical staff should not address people by their diagnosis.
- Families may have many questions and medical staff should be ready and available to answer them.
- Medical staff or caregivers should not argue with a patient who has dementia
- Support services and materials such as ADRC brochures and contact information should be readily available.
- Sensitivity training would be beneficial for medical staff and advocates— not only for the patient's benefit but also for the family, to be sure all their concerns are heard.

It is also recommended that home care agency and hospital staff working with people who have Alzheimer's or dementia participate in support groups to listen to the concerns of the families involved in care. Caregivers for people with Alzheimer's and dementia must adopt a truly patient- and family-centered approach to care.

Thank you to Alzheimer's Disease Resource Center, Bayshore NY <http://www.adrcinc.org/>