Communication with Family Members of Residents with Alzheimer’s Disease

Communication with families is important. This is especially true for families of residents with Alzheimer’s disease (AD) because families may not be able to rely on the resident for factual information. They will depend on the facility staff more than any of the other families in the facility. They experience all the difficult feelings any family does when a loved one moves to a long-term care facility, but AD makes it even worse. Some AD residents “improve” or start looking better with the structure, predictability, and simple routine of the facility. Families may have difficulty accepting that “a place with strangers” makes their relative more comfortable than they could.

Because of the behavioral and communication problems associated with AD, families will expect the staff and doctors to routinely check for all signs of potential illness, infection or injury. Many families feel more secure once the AD patient is in a health care setting with staff trained to observe and treat acute conditions. It’s “not knowing” that makes so many families unsure—is he/she in pain? Hungry? Scared? Abused? Neglected? Injured? Ill? The staff’s goal will be to share their understanding of the resident and the disease process with the family—gradually, not all at once.

Families, as well as residents, need orientation to facility routines. They appreciate written information with names to speak to and what to speak to them about. They appreciate consistent staff they can learn to trust and work with over time. They need clear procedures for the “what-ifs” of care. What will be done for acute illnesses or injuries? When will they be notified? How can they communicate with the attending doctor? Are they welcome at meals, activities?

On admission, the primary family caregiver can be the best source of information. Many families prepare letters or written descriptions of routine care and preferences for the resident’s chart upon admission. The fewer changes in care routine during the admission adjustment, the more quickly the resident will adjust. However, families must be prepared for the unexpected, i.e., baths are given only twice a week, meals are served in a dining room.

Many families feel their questions might appear stupid or might aggravate the staff in a way that will encourage staff to “take it out on their relative.” Staff should give families opportunities to talk when they are not rushed either special meetings for new families, or suggest the best time of day for them to talk with staff. It’s staff’s attitude of interest, availability, and willingness to work with them in the care of their relative that will be evaluated. Most family members can’t evaluate a staff member’s technical competence. But the manner in which he/she interacts with their relative tells them a lot about the staff.

Be prepared for AD families to have difficulty with visiting. Many are disappointed when their family member does not remember the visits, accuses them of stealing, is apathetic or withdrawn, or looks messy. Families appreciate suggestions on how to improve the quality of their visits for themselves and for the patient. Facilities with active family visitors are generally seen as ideal places to work or live.

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