

## Working with Families of Hospitalized Older Adults with Dementia

By: Katie Maslow, MSW, Gerontological Society of America; Mathy Mezey, EdD, RN, FAAN, NYU  
Rory Meyers College of Nursing; Geri Richards Hall, PhD, ARNP, CNS, FAAN, Banner Health

**WHY:** When a person with dementia is hospitalized, the family is anxious about the medical condition that caused the hospitalization and also about how the person will react in an unfamiliar setting and whether the hospital staff will be able to understand and/or provide care for the person. Many people with dementia become more confused and agitated in the hospital (Cunningham, 2006; Sampson, White, Leurent, et al., 2014). Families are often surprised and frightened by these changes and anxious about how they will manage the person at home (Boltz, Chippendale, Resnick, & Galvin, 2015). If the person lives in a care facility or attends adult day care, the family may fear that the facility or program will refuse readmission. Thus, families of hospital patients with dementia have many reasons for heightened anxiety. Spouses of hospital patients with dementia were more likely than spouses of hospital patients with other conditions, such as cancer, heart failure, and stroke, to die within the year of their spouse's hospitalization (Christakis, & Allison, 2006).

**TARGET POPULATION:** Families and significant others of hospital patients with dementia.

**BEST PRACTICES:** Nurses should seek to work with families to improve care and outcomes for hospital patients with dementia. Three approaches are recommended:

- 1) Ask the family to provide information about the person's usual functioning to help hospital staff provide care for the person. The form on the next page, completed by the family or with a nurse, can be used as is or modified by deleting questions that appear on other hospital forms or adding questions about issues of special concern. Families are the best source of information about the patient's pre-hospital abilities in areas, such as drinking, eating, toileting, and mobility (UCSF Memory and Aging Center, Tips for Hospitalization; Nichols, 2006; Smith-Hunnicut, 2005). Patient functioning in these areas is sometimes lost or diminished, even in a short hospital stay. The form provides a baseline that can be used to set goals for maintaining patient functioning during the hospital stay and planning restorative care.
- 2) Involve the family in care. While families differ in their capability and preferences about how to be involved, many are eager to help when they are encouraged to do so (Nichols, 2006; Smith-Hunnicut, 2005). Important roles for families include giving the patient a feeling of continuity, belonging, and comfort in an unfamiliar environment; providing social stimulation; assisting with care, including drinking, eating, walking, other activities; and suggesting ways to give personal care that minimize patient agitation. A family that participates actively in care can make the difference between fear and comfort for their loved one with dementia.
- 3) Provide information for the family. Families differ in what they know about dementia and dementia care, and many families do not know how to provide post-discharge care for the medical condition(s) that caused the hospital admission (Nichols, 2006; Naylor, Stephens, Bowles, & Bixby, 2005). They should be encouraged to observe, participate in, and discuss care and treatments as the person with dementia often cannot understand what hospital staff communicate well enough to pass it on to the family. Families must begin discharge planning at admission, with assistance as needed, to find resources and make arrangements for home care, equipment, and transportation. In-hospital physical and occupational therapy consultations help the family to learn to provide safe mobility and care. In all cases, discharge instructions, including medications and treatment, must be given to both the patient and the family, since the patient will often not be able to remember them.

### MORE ON THE TOPIC:

Best practice information on care of older adults: [www.ConsultGeri.org](http://www.ConsultGeri.org). See "Family Caregiving"

Boltz, M., Chippendale, T., Resnick B., Galvin, J. (2015). Anxiety in family caregivers of hospitalized person with dementia. *Alzheimer Disease and Associate Disorders*, 29(3), 236-241.

Christakis, N.A., & Allison, P.D. (2006). Mortality after the hospitalization of a spouse. *NEJM*, 354(7), 719-730.

Cunningham, C. (2006). Understanding challenging behaviour in patients with dementia. *Nursing Standard*, 20(47), 42-42.

Naylor, M.D., Stephens, C., Bowles, K.H., & Bixby, M.B. (2005). Cognitively impaired older adults: From hospital to home. *AJN*, 105(2), 52-61.

Nichols, J.N. (2006). Windows to the heart: Creating an acute care dementia unit. In N. M. Silverstein, & K. Maslow, *Improving hospital care for people with dementia*. NY: Springer Publishing Co., Inc.

Sampson, E.L., White, N., Leurent, B., Scott, S., Lord, K., Round, J., Jones, L. (2014). Behavioural and psychiatric symptoms in people with dementia admitted to the acute hospital: Prospective cohort study. *British Journal of Psychiatry*, 205(3), 189-196.

Smith-Hunnicut, N. (2005). Dementia-Responsive Acute Care at Mission Hospitals in Asheville, North Carolina. *North Carolina Medical Journal*, 66(1), 72-74.

UCSF Memory and Aging Center. (2016). Tips for hospitalization. <http://memory.ucsf.edu/caregiving/hospitalization>

U.S. Department of Health and Human Services, National Institutes of Health, National Institute on Aging. (2015). 2014-15 Alzheimer's Disease Progress Report: Advancing Research Toward a Cure. NIH-NIA. Available at <https://www.nia.nih.gov/alzheimers/publication/2014-2015-alzheimers-disease-progress-report/introduction>

## Information for the Hospital Team about a Patient with Memory Problems\*

PATIENT'S NAME: \_\_\_\_\_ What does he or she like to be called? \_\_\_\_\_

Patient lives: \_\_\_\_\_  
(at home? alone, or with you or someone else? in a nursing home or other facility?)

Person completing this form: \_\_\_\_\_  
(name and relationship to the patient)

Home phone: \_\_\_\_\_ Cell phone: \_\_\_\_\_

1. Patient usually drinks these liquids best: \_\_\_\_\_

2. Patient usually drinks from a cup or glass: with a straw? or without a straw? (circle one)

3. Does the patient wear dentures? \_\_\_\_\_ If so, does the patient have the dentures with him/her? \_\_\_\_\_

4. Patient usually eats these foods best: \_\_\_\_\_

5. Patient eats best if he/she: (circle all that apply)

- |                                      |                                    |
|--------------------------------------|------------------------------------|
| a. is helped with tray set up        | d. is reminded to chew and swallow |
| b. is shown how to use spoon or fork | e. is given smaller portions       |
| c. is given finger foods             | f. is fed                          |

6. Does the patient wear glasses? \_\_\_\_\_ If so, are the glasses with him/her? \_\_\_\_\_

7. Does the patient wear hearing aid(s)? \_\_\_\_\_ If so, are the hearing aid(s) with him/her? \_\_\_\_\_

8. Does the patient speak and understand English? \_\_\_\_\_ If not, does the patient speak and understand another language?  
If so, what language? \_\_\_\_\_

9. Does the patient express his or her needs verbally? (thirst, hunger, go to the bathroom?) \_\_\_\_\_

10. Does the patient usually go to the bathroom alone or need help or supervision? \_\_\_\_\_

11. How does the patient usually express pain? \_\_\_\_\_  
(verbally? facial expression? agitated body movements?)

12. Does the patient usually need help with: (Please write yes or no for each activity)

- |  |   |
|--|---|
| a. Bathing? _____                            | Usual bath time? _____  |
| b. Brushing teeth and mouth care? _____      |   |
| c. Getting from bed to chair and back? _____ |   |
| d. Dressing _____                            |   |
| e. Walking _____                             | Does he/she usually use a cane, walker, or wheel chair? _____ |

13. Has the patient fallen recently? \_\_\_\_\_ How often? \_\_\_\_\_ Why? \_\_\_\_\_

14. How does the patient act when he or she is anxious or frightened? \_\_\_\_\_

15. Does the patient get angry or physically aggressive? \_\_\_\_\_

16. What helps to calm or comfort the patient at difficult times? \_\_\_\_\_

17. Does the patient usually watch TV or listen to the radio? \_\_\_\_\_

18. Does the patient have an advanced directive? \_\_\_\_\_

19. Is there anything else you want us to know about the patient? \_\_\_\_\_

20. What else does the family want to know from the physician or hospital staff? \_\_\_\_\_

\* Adapted from forms developed by the Dementia Responsive Care Initiative, Mission Hospitals, Asheville, NC; and Mittleman, M., & Epstein, C. (2003). *The Alzheimer's health care handbook*, pp. 179-184. NY: Marlowe & Co.