

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

CONSUMER FACTSHEET: DEMENTIA CARE CONSIDERATIONS

Accessing appropriate care and services for someone with dementia can be daunting. In this fact sheet, we provide some questions to ask and considerations for individuals and families who are faced with making choices about dementia care and advocating for the care and services that are appropriate and beneficial for the individual.

These questions and considerations were adapted from a dementia care survey (inspection) process piloted by the U.S. Centers for Medicare and Medicaid Services. Though they are geared to assessing whether a nursing home is complying with minimum standards, we believe that they can be useful for evaluating whether dementia care is good and appropriate in any setting.

QUESTIONS TO ASK & CONSIDER

- Does the nursing home have specific policies and procedures related to dementia care (whether or not they have a special dementia unit)?
- Do resident care policies and procedures clearly indicate a systematic process for the care of residents with dementia?
- Does the nursing home look systematically at ways to structure the care processes around the residents' individual needs and not around staff needs or routines (including short staffing)?
- Does the overall philosophy of care in the nursing home acknowledge behaviors as a form of communication?
- Is that philosophy evidenced in the care practices in the facility? How?
- Are care staff actively trying to understand the meaning behind dementia-related behaviors and responding in a way that is appropriate and beneficial to the resident?
- Is it evident, through conversations with facility staff and leadership, that nationally recognized dementia care guidelines or programs (for examples see the document *NonPharma Approaches to Dementia Care* on www.nursinghome411.org) are the basis of care for people with dementia in the nursing home?
- Do resident care policies and procedures clearly outline a systematic process for the care of residents with dementia?
- Are staff receiving dementia care training? If so, what kind and how often?

PRACTICES TO OBSERVE & CONSIDER

- **Observe** for language or routines that could have an impact on dignity and/or function, e.g.:
 - Use of bibs;
 - High percentage of residents wearing socks/non-skid socks and institutional gowns instead of their own clothes and shoes;
 - Residents with soiled hands or nails, unshaven or with hair not combed;
 - Failure to respond to residents' communication/behavioral manifestations of distress/emotional to prevent escalation of distress; and
 - Attempts to keep residents "quiet" or prevent them from moving around versus efforts to walk or talk with residents who appear distressed.
- **Observe** for social dining atmosphere or individualized dining setting (as appropriate) with staff sharing the dining experience with residents (not standing over them).
- **Observe** for staff talking with residents, not talking only with other staff or ignoring residents. Observe for culturally appropriate meals.
- **Observe** for whether or not staff assesses the environment regularly for too much or too little noise, light and stimulation. (Since this may be difficult to ascertain during observations alone, speak with staff about how they address environmental issues for individuals with dementia).
- **Observe** for other basic dementia care approaches such as:
 - Using soft, low voice and speaking where resident may read lips/see face clearly;
 - Not approaching resident from behind;
 - Providing adequate time during resident care and meals (not rushing);
 - Encouraging maximal independence (not performing activities/care routines that resident could perform him/herself if given adequate time and cues);
 - Encouraging time outdoors and resident involvement in physical activities;
 - Redirecting resident away from high stress environments;
 - Allowing a resident to remain in preferred location (e.g., to remain in bed) if safe, and re-approaching that resident later on if they express a desire/choose to remain where they are (staff recognizing this as preference/choice, even in someone who has dementia);
 - Providing stimulation (to avoid boredom);
 - Ensuring an adequate number and type of activities on all shifts, including weekends;
 - Addressing loneliness/isolation; and
 - Appropriately limiting choices to avoid frustration/confusion.
- **Assess** for adequate sleep and individualized sleep hygiene in care plan (sleep facilitators, such as reducing interruptions for continence care or pressure relief through use of appropriate continence products and mattresses); sleep log or diary if indicated. Assess for residents sleeping often during activities.
- **Evaluate** for adequate pain assessment in all residents with particular attention to those with difficulty communicating about pain.
- **Assess** for issues during care transitions. For example, was there a unit or room change? What prompted this change? How was information transferred effectively among care providers.

RESOURCES

- WWW.NURSINGHOME411.ORG. LTCCC's website includes materials on the relevant standards for nursing home care, a listing of antipsychotic drug names and other resources.
- WWW.THECONSUMERVOICE.ORG. The Consumer Voice has numerous materials and resources for residents, family members and LTC Ombudsmen.