Advanced Dementia: Frequently Asked Questions

The Centers for Disease Control listed Alzheimer’s Disease as the 6th leading cause of death in 2006 (Heron and colleagues, 2009). Indeed, a 2009 Harvard study (Mitchell and colleagues) revealed a course of clinical decline that highlights the very physical, and terminal, nature of dementia (not just Alzheimer’s), with 6 month mortality figures that suggest more specific prognostic markers for referral to comfort care only.

In light of the research, we offer some FAQs (Frequently Asked Questions) about hospice, dementing illness, and end-of-life care:

1) Is dementia a terminal condition?
2) What markers indicate a 6 month prognosis?
3) What can hospice do for the patient?
1. Is dementia a terminal condition?

Too often we forget that progressive dementing diseases are terminal conditions affecting the body as well as the mind. For instance, the Centers for Disease Control and Prevention (2011) list Alzheimer’s disease as the 6th leading cause of death, claiming more than 74,000 lives in 2007. While “dementia” is a term used to describe many conditions of cognitive decline, it is caused most often by progressive diseases of the brain that also physically shut down the body and organ systems.

Prognosis is commonly over-estimated. For instance, in one study, only 1% of residents with advanced dementia who were admitted to a nursing home were given a prognosis of 6 months or less. However, 71% of these residents were in fact dead within six months (Mitchell, Kely & Hamel, 2004).

It is not uncommon for persons with advanced dementia to have tests ordered that would never be ordered for a patient with another terminal diagnosis. For instance, a study by Mehta, Fung, Kistler, Chang and Walter (2010) revealed that 18% of women with severe dementia received mammograms despite a life expectancy that was clearly shorter than would allow them to benefit from treatment if cancer were found. Not only were these women subjected to the discomfort of the test, but there was no real reason or benefit for them to undergo the procedure.

Dementing conditions are frequently NOT recognized as terminal. As a result, they do not receive the palliative, comfort care their cognitively intact peers receive (Long, 2009; Lussier, Bruneau & Villalpando, 2011).

2. What markers indicate a 6 month prognosis?

Mitchell and colleagues (2009) conducted a multi-site prospective study of 323 nursing home residents with advanced dementia to come to a better understanding of the clinical course of the later stages.

Adjusting for age, sex, and disease duration, the 6 month mortality rate of residents with advanced dementia was:

- 46.7% for those who also had pneumonia
- 44.5% for those who also had a febrile episode
- 38.6% for those who also had eating problems (defined in the study as ‘weight loss, problems chewing or swallowing, refusal to eat or drink, suspected dehydration, and persistently reduced oral intake’).

Of particular note, eating problems could be considered a hallmark of the terminal phase. For instance, across the 18 month interval of the study, among those few patients who did not exhibit eating problems, the 500 day survival rate was 90%.

Below are Medicare hospice eligibility guidelines for people with dementia as described by the Alzheimer’s Association (Gould & Simon, 2008) and the National Hospice and Palliative Care Organization.

<table>
<thead>
<tr>
<th>Hospitalization in the last year for at least one of the following:</th>
<th>All of the following:</th>
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<tr>
<td>Aspiration pneumonia</td>
<td>Urinary and fecal incontinence</td>
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<tr>
<td>Upper urinary tract infection</td>
<td>Unable to ambulate without assistance</td>
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<tr>
<td>Septicemia</td>
<td>Unable to dress without assistance</td>
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<tr>
<td>Decubitus Ulcers, multiple, stages 3-4</td>
<td>Unable to bathe properly</td>
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<tr>
<td>Fever recurrent after antibiotics</td>
<td>Inability to speak or communicate meaningfully</td>
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<td>Inability or unwillingness to take food or fluids sufficient to sustain life</td>
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3. What can hospice do for the patient?

Promoting quality of life for persons with advanced dementia is especially challenging. In fact, the less communicative the patient, the more skilled the family (or staff for nursing home residents) needs to be to identify problems and provide the comfort and quality of life that confused and non-verbal patients deserve.

At Crossroads Hospice, our staff has received additional Alzheimer’s and dementia training and education to ensure patients with dementia and Alzheimer’s disease receive the most competent and professional care available.

- **Reduction in aggressive or burdensome treatments.** Because of the patient’s inability to comprehend more than the presence or absence of pain and discomfort, many treatments must be evaluated relative to the distress they are likely to cause an extremely confused individual. Moreover, if the patient is clinically in the advanced phase of dementia, there are treatments that could appropriately be avoided, such as dialysis or a ventilator, that would similarly be avoided if the patient were in the end-stage of cancer. Our team of experts can help families work through the risks and benefits of aggressive treatment.

- **Ability appropriate stimulation and engagement.** Persons with dementia have needs for engagement that walks the fine line between boredom and sensory overload (Cohen-Mansfield, Thein, Dakheel-Ali, Marx, 2010). Many disruptive behaviors such as restlessness and agitation can be attributed to lack of stimulation or engagement. At the same time, emotional outbursts and aggression can be triggered when the environment puts more demands on the patient than the patient can handle (Neugroschl, 2002).

- **Improved social connections.** Too often the focus in dementia is on what the patient can no longer do. We focus on assisting the family and facility caregivers to support and enhance the patient’s strengths and teach communication skills that are most likely to generate patient/family positive interactions. Meaningful social connections help the patient to feel included, less frightened and isolated. They also help caregivers to stay engaged and attentive, finding joy and meaning with the patient, even when standard conversation is no longer an option.

- **Attention to spiritual needs and comfort.** People in advanced dementia may not be able to verbally express their spiritual needs, but they often respond positively to familiar rituals of their spiritual traditions (Jewell, 2011). With cultural sensitivity, our staff can provide spiritual comfort through appropriate use of prayer, song and touch. In addition, we can assist with the reading of scripture, display of religious objects, and eating of ritual foods, all activities that can evoke feelings of transcendence and inclusion in the patient’s faith community, even if group worship is no longer an option.