# End-of-life care for people with progressive dementias: promoting quality of life.

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Progressive dementias include Alzheimer's disease, vascular dementia, dementia with Lewy bodies and fronto-temporal dementia. Although symptoms of these diseases differ in earlier stages, they are very similar once they reach an advanced stage. Advanced progressive dementia may be considered to be a terminal disease because there is no treatment that will cure it or stop its progression. Therefore, comfort and quality of life are two important goals of dementia care at this stage of the disease. Three aspects of care have to be addressed to promote quality of life. People with dementia should be provided with meaningful activities, receive appropriate medical care, and their behavioral symptoms of dementia have to be treated (Fig). Promotion of quality of life should continue to be the goal of care in advanced dementia until the end of life because progressive dementias do not result in a persistent vegetative state. Therefore, even people with advanced dementia require pain control, symptom management and attention to their psychological and spiritual needs.

**1. Meaningful activities:** Meaningful activities have to be provided because individuals with dementia have deficit of the executive function and are not able to initiate these activities themselves. For moderate dementia, group activities should involve physical exercises, simple mental exercises (e.g., word games, trivia, sorting), sing-alongs and creative activities such as simple crafts. Integrating beverages and snacks as part of meaningful activities in a social setting throughout the day improves nutrition and hydration. The activities should be provided as a continuous activity programming, available for most of the waking hours, 7 days/week. Effective program of meaningful activities results in decreased need for psychoactive medications, decreased agitation, improved nutritional status and may also result in decreased incidence of falls [1].

As dementia progresses, some individuals may not be able to participate in group activities. They may nap during the day and are unable to communicate verbally. The appropriate activity program for these individuals is Namaste Care [2]. Namaste Care takes place in a room with soft music, lower lights and scent of lavender. In this peaceful environment residents with advanced dementia are gathered so they are not isolated in their rooms or placed in a hallway. A Namaste carer engages residents in activities of daily living provided as meaningful activities, e.g., washing and moisturizing residents' face, providing loving touch without gloves, and talking to the resident. The emphasis is on engaging the resident instead of on completion of the task. Residents are placed in comfortable recliners and are offered realistic dolls or stuffed cats and dogs if these items bring them comfort. Liquids are offered in small sips throughout the Namaste Care day. The program is an enhanced nursing care, should be provided 7 days/week, and does not require additional staffing.

**2. Medical care:** Medical care should carefully balance burdens and benefits of medical interventions because even simple procedures produce discomfort for an individual who does not understand the reason for such a procedure. Aggressive procedures that may not be appropriate in individuals with advanced dementia include cardiopulmonary resuscitation, transfer to acute medical care settings, use of antibiotics in treatment of generalized infections, and tube feeding [3]. Cardiopulmonary resuscitation is rarely successful and often results in injuries and extended stay in an intensive care unit that pose a great burden for individuals with advanced dementia. Even those few who are discharged from a hospital are much more functionally impaired than they were before cardiac arrest.

Acute care setting is not suitable for individuals with advanced dementia who try to remove catheters, have to be restrained, develop pressure ulcers, and are poorly nourished. It is better to treat pneumonia and other infections without transfer because treatment in residential setting, using oral or intramuscular antibiotics, is equally or more effective as treatment in a hospital and results in less functional decline. However, use of antibiotics for treatment of generalized infections should consider that antibiotics are less effective because of the recurrent nature of pneumonia and urinary tract infections. Antibiotic treatment may just prolong dying instead of leading to long-term recovery and comfort may be maintained without antibiotics by treatment with analgesics (eg., morphine), antipyretics and oxygen if necessary. Overuse of antibiotics leads to adverse effects that include development of resistance to antibiotics (e.g., MRSA) and Clostridium difficile infections.

Advanced dementia results in food refusal, choking on food and liquids and eventually inability to open mouth and swallow. These problems may be decreased by modification of diet texture, treatment with antidepressants and appetite stimulants (e.g., dronabinol), and by careful hand feeding. Tube feeding should not be used in people with advanced dementia because it does not provide any benefits. It does not prevent aspiration pneumonia and might actually increase its incidence. Tube feeding may increase patient's discomfort, may require restraints, and eliminates enjoyment of tasting food and of contact with caregivers during the hand feeding. It is important to realize that patients who are dying do not experience thirst and hunger and the only discomfort may be caused by dryness of mouth that can be eliminated by small sips or by spray of artificial saliva. There is an advantage of dying while dehydrated because dehydration decreases respiratory and gastrointestinal secretions eliminating need for suctioning and preventing vomiting and diarrhea. Dehydration also decreases the perception of pain because endorphins are released together with vasopressin.

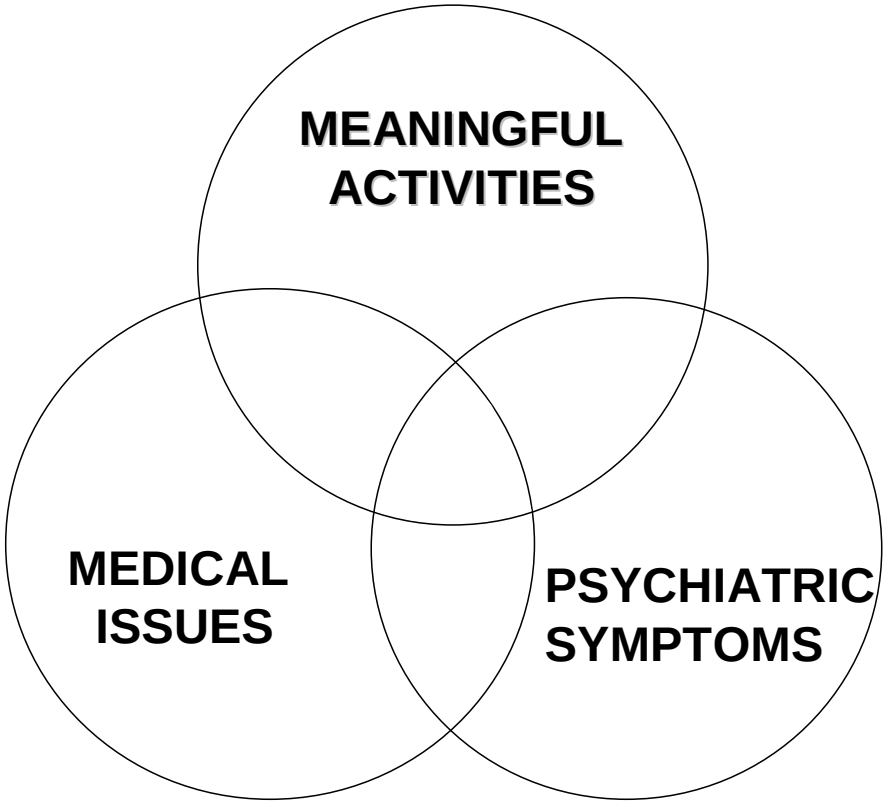
**3. Behavioral symptoms:** Treatment of behavioral symptoms of dementia is as important as treatment of pain in individuals with cancer. It is important to distinguish symptoms that occur when an individual is solitary and those that occur when the individual interact with others. The most common behavioral symptoms that occur when the individual is solitary are agitation and apathy, while the most common symptom during interaction with others is resistiveness to care [4]. Agitation may be caused by physical and environmental stimuli; e.g., pain, hunger, thirst, need for toileting, inappropriate temperature, and noise. It is important to eliminate these stimuli before considering that the symptoms are caused by dementia. Both agitation and apathy should be first managed by providing meaningful activities. However, if agitation persists, it could be due to depression or hallucinations and delusions. Antidepressant treatment is often effective and antipsychotics should be used only if the patient experiences bothersome delusions or hallucinations.

Resistiveness to care is often due to lack of understanding of caregiver's intentions when an attempt is made to provide care. The patient resists unwanted attention and if the caregiver insists on providing care, the patient may strike out to defend him/herself. Such an individual is sometimes considered to be aggressive or abusive, but the patient actually considers the caregiver to be an aggressor. The second most important factor causing resistiveness to care is depression. Depression may actually result in a behavior that is considered abusive by the caregivers even in absence of resistiveness to care [5].

Resistiveness to care may be decreased or eliminated by improving communication between the patient and the caregiver. The patient may not understand spoken explanation because of aphasia but may understand the caregiver's intentions if he/she is brought to familiar environment suggesting the activity, e.g., barber shop or home-like bathroom. Resistiveness to care may be also avoided by delaying the care or by distracting the patient by reminiscence during care. Resistiveness to care is most common during bathing but it may be eliminated by substituting bed (towel) bath for shower or tub bath. Bed bath is equally effective in cleaning and eliminating microbial counts on the skin and is much better accepted by the patients.

If improved communication is not sufficient to eliminate resistiveness to care or if abusive behavior occurs outside of the care situation, antidepressants should be the first medication to use. Antipsychotics should be used as the first line therapy only if the resistiveness to care or abusive behavior is clearly caused by delusions or hallucinations. Antipsychotics have many adverse effects including increased incidence of sudden death and increased mortality rate. In some cases, however, antidepressant treatment may not be completely effective and requires addition of an antipsychotic to enhance its effectiveness.
Advanced dementia inevitably diminishes quality of life. However, by addressing the three important aspects of dementia care listed above, it is possible to promote quality of life until the end of life.

**Figure**



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