

End of Life Care in Dementia

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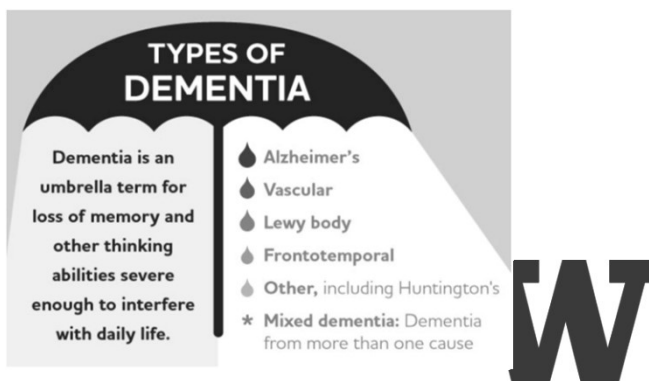
Outline

- > **Definitions – What is “Advanced Dementia”**
- > **Clinical Picture – What does it look like?**
 - **Disease progression (Mentation and Mobility)**
- > **Treatment and Care**
 - **Anticipatory Guidance**
 - **Tools to achieve treatment/care aligned with values/goals (Medications and Matters Most)**
 - **Palliative Care and Hospice**
- > **Cases**



Definitions:

- > **Dementia** – Broad term for diseases of the brain that affect thinking, behavior, and memory
- > **Types of Dementia**
 - Alzheimer’s Dementia
 - Vascular Dementia
 - Parkinson’s Dementia
 - Lewy Body Dementia
 - Frontotemporal Dementia
 - Mixed Dementia



<https://www.alz.org/alzheimers-dementia/what-is-dementia>

Understanding

Is Dementia “terminal”?

ORIGINAL ARTICLE

The Clinical Course of Advanced Dementia

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<p>Article Figures/Media</p> <hr/> <p>37 References 1037 Citing Articles Letters</p> <p>Abstract</p> <hr/> <p>BACKGROUND</p> <p>Dementia is a leading cause of death in the United States but is underrecognized as a terminal illness. The clinical course of nursing home residents with advanced dementia has not been well described.</p>	<p>October 15, 2009 N Engl J Med 2009; 361:1529-1538 DOI: 10.1056/NEJMoa0902234</p>
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CASCADE Study (Choices, Attitudes and Strategies for Care of Advanced Dementia at the End-of-Life)

- > **Recognized Advanced Dementia as a terminal illness by following progression of condition (2009)**
 - 323 pts w/ Advanced Dementia in 22 SNFs (Boston)
 - Median survival = 478 days (comparable to terminal cancer)
 - Most pts died from PNA, febrile episode (infection), eating problems (40-50% dying w/in 6 months of onset)



CASCADE Study: Important Findings

- > **Dyspnea, pain, and agitation in 40-50% of pts and more common as death neared (uncontrolled/untreated symptoms)**
- > **Many pts were hospitalized in last 3 months of life**
- > **However, if proxy perceived pt had ≤ 6 months prognosis and understood probable medical complications, pt far less likely to receive “burdensome” interventions in last 3 months**

- > **Recognition of Advanced Dementia as a terminal condition could lead to better anticipatory guidance and conversations that could result in improved values/goals aligned care.**



Advanced Dementia

- > **Advanced dementia is the final stage of dementia.**
 - **Dementia gets worse over time.**
 - **Usually reaches final stage 3-6 years after being diagnosed**
 - **Dementia is a terminal illness**

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Advanced Dementia: What does it look like?

- > **Profound memory deficits such as inability to recognize family members**
- > **Eventual loss of speech**
- > **Total functional dependence**
- > **Bowel and bladder incontinence**
- > **Inability to ambulate independently**

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Medical Complications of Advanced Dementia

- > **Most common medical complications:**
 - **Eating problems (90% of pts w/ Advanced Dementia will develop)**
 - **Infections (almost 50% of pts w/ Advanced Dementia)**
- > **Pts w/ Advanced Dementia commonly die from these complications caused by the disease**
 - **May be helpful to think of Advanced Dementia pts like pts w/ widespread advanced cancer who are more prone to infections which can be life-ending complications due to overall weakened defenses (it is the underlying illness that leads to complications and death)**



That was the medical part, how do you talk to families and/or decision-makers about this?

- > **When/How do you bring up the idea of dementia as a terminal condition?**
- > **When/How do you discuss complications like eating problems and infections that could be life-ending?**
- > **We need effective language and communication tools in order to have conversations about potentially scary/stressful topics to successfully learn about pt and proxy values and goals and to provide value/goal-aligned treatment and care (it's a process)**



Matters Most: How do you get there?

- > **Primary Palliative Care**
- > **Serious Illness Communication**
- > **Patient Priorities Care**

- > **Compassion, good communication skills/tools, patience and grace**



Consider Timing

- > **One size does not fit all**
- > **Dementia can have a long course (years vs months)**
- > **Consider where in disease trajectory pt is compared to where understanding of pt/proxy is (prognostic discordance)**
- > **Consider how much rapport you have built up with pt/proxy**
- > **Sometimes hospitalizations or paroxysmal events might present opportunities to open the door to conversations**



First things first:

> Prepare

- Longstanding relationship or new patient?
- What are you hoping to accomplish during visit/in the long run (short term/medium term/long term goals)?
 - > May need several visits depending on where you're starting from
 - > Who should be at the visit or family meeting? (Pt and proxy? Just proxy? Family members? Caregivers?)
- Chart review: How advanced is pt's dementia?
- Cultural concerns? Interpreter needed?
- Is this a telehealth (virtual/by phone) visit/conversation?



Palliative Care Framework/Approach:

- > Introductions/Greetings (helpful to get names and relation to pt/proxy)
- > Purpose of Family Meeting
 - Today, I'm hoping to talk about how we can provide the best medical care for (your mother/father, pt's name).
 - We want to make sure we understand what is most important to you as we think about his/her medical care moving forward.
- > Check In (may give you insight into where pt/proxy are starting from)
 - Is it okay if I start with a check-in?
 - How have things been going at home/at (the nursing home—try using the facility name if possible)?
 - Are there any questions you have about (pt's) care that you want to make sure we get to today?



Palliative Care Framework/Approach: Continued

- > **Assess Understanding**
 - If pt and proxy are relatively new to you:
 - > About how long ago was (pt) diagnosed with dementia? (Months? Years?)
 - > Since then, has anyone talked to you about what challenges pts and their families can face over time?
 - > Is it okay if we talk a little bit today about some things to think about and prepare for?
 - If pt and proxy are established:
 - > As you know, your mom/dad has had dementia for a long time and is now in the final stages of this condition. Over time, dementia affects not just the brain, but the whole body. In addition to serious memory problems, he/she now has trouble moving around without help.



Language around Advanced Dementia as a Terminal Illness:

- > Some problems are very common in advanced dementia. Almost all people with advanced dementia develop problems eating. Infections are also very common.
- > People with advanced dementia often die from these problems. Unfortunately, at this time, we don't have any treatments or medicines that can reverse or stop dementia or these complications.
- > (If helpful, can consider this comparison) Advanced dementia is similar to widespread advanced cancer in that we have no cure yet. In the same way that cancer can weaken the body and its defenses, advanced dementia can also make it harder to fight infections or have the strength or appetite to eat like a person would if they were healthy.



Language around Goals/Values:

> Values Triad: Comfort, Longevity, Independence

- It helps us plan the best treatment for (pt) when we know what matters most to you. We can match (pt's) medical care to your goals and values.
- For some people and their families, being comfortable and having any symptoms like pain or trouble breathing treated aggressively is the most important. Even if this means not providing more uncomfortable medical treatments that could help them live longer. (Comfort as a priority)
- If the main goal is to live as long as possible, the treatments we use might require procedures that cause discomfort. (Longevity as a priority)
- Balancing being comfortable and living longer means thinking about the trade offs in each situation. It might help to think about whether a treatment would help to get (pt) back to where he/she was before a setback. (Function/Independence as a priority)



Supportive Language Around Difficult Decisions:

> Be supportive:

- Making these decisions is not easy. This is a very loving decision you are making for your mom/dad. You are an incredible advocate for her/him.

> Give permission (especially if there is family conflict or guilt), this too is support:

- It is okay to change your mind
- It is okay to think about what decision will keep your family together/what decision might result in the least amount of regret. These are not easy decisions.
- I can see how hard you're trying to balance what you know your mom/dad would want in this situation with what your brother/sister wants for them.



Hot Button Topics:

- > **Eating Problems**
- > **Treating Infections**
- > **Hospitalization**
- > **When to refer to Palliative Care**
- > **When to refer to Hospice**



Eating Problems

- > **Almost 90% of people w/ advanced dementia have eating problems**
- > **When eating problems start, it often signals a much shorter prognosis**
- > **Etiology:**
 - **The brain's control of muscles and nerves involved in chewing and swallowing is lost (may forget to swallow)**
 - **Pt unable to feed themselves**
- > **Difficulty chewing and swallowing leads to one of the most common complication in advanced dementia – aspiration**



Eating Problems

- > **Work up:**
 - Look for dental issues, new infection, stroke
- > **Treatment:**
 - Offer favorite foods, reduce portion size, change food texture, try to have pt eat with others
 - Hand feeding – takes a long time, intake may vary, is comfort-focused
 - Tube feeding – allows for ease of administration of consistent amount of food, fluid, and medications



Tube Feeding

- > **Does tube feeding prevent aspiration?**
 - **NO!** Tube feeding **DOES NOT** prevent or reduce the risk of aspiration.
- > **Does tube feeding help someone with advanced dementia live longer?**
 - **NO!** Tube fed patients w/ advanced dementia often continue to lose weight, may have diarrhea, may need to be restrained or given sedating medications (to prevent them from pulling out the feeding tube), miss out on tasting food and social interaction during mealtime



Language around Eating Problems:

- > **Eating problems are expected in the end stage of dementia. When eating problems start, we know that the end of life is getting closer. This is a natural part of the process of any terminal illness, including advanced dementia.**
- > **What about starving to death?**
 - **From all of the medical evidence and personal experiences we have seen, even when people are eating and drinking very little, it does not appear that they sense hunger or thirst.**
 - **Eating less is something we expect in advanced dementia. It is a natural part of the disease process. The dementia causes the body to slowly shut down.**



Cultural/Value Considerations

- > **You have not failed if you can't "convince" a proxy NOT to put a feeding tube in someone w/ advanced dementia**
- > **Some cultures/communities pressure proxies into making that decision. Some people are vitalists.**
- > **Food = Love in many cultures**
 - **It is important to provide anticipatory guidance around the amount or intake decreasing and letting families know it is not a rejection of their love or efforts, but a symptom of advanced dementia that their loved one cannot control.**



Treating Infections:

- > **Most pts w/ advanced dementia get infections which is often a sign that the end of life is near**
- > **PNA (~40% pts) and UTIs are most common**
- > **Pts treated w/ antibiotics may live a few months longer (trade off is possible side effects/discomfort)**



Language around Treating Infections

- > **In advanced dementia the body's defenses that fight off bacteria are weakened. Although a urinary tract infection or even pneumonia might not be a big issue for young healthy people, it can be a sign that the end of life is near for people with advanced dementia.**
- > **Pneumonia and urinary tract infections are two of the most common infections in advanced dementia. An important decision is whether or not to start antibiotics. If our goal is to keep (pt) as comfortable as possible, it might not be necessary to use antibiotics. Antibiotics can come with side effects that can be harmful.**
- > **Treating infections depends on goals and clinical judgement.**



Hospitalization: Planning ahead for acute illness

- > **Acute issues can come up for pts w/ advanced dementia – Heart attack, stroke, GI bleed, infections, etc**
- > **Advantage: access to higher level tx (ICU, surgery, cath lab)**
- > **Disadvantages:**
 - **Hospitalization can be traumatic and frightening to pt w/ advanced dementia**
 - **Pt may not understand what is happening, can be uncomfortable (physically)**
 - **Being in unfamiliar environment w/ strangers can trigger agitation, unfamiliar routine**
 - **Risk of infection, bed sores, delirium**



Hospitalization: Planning ahead for acute illness

- > **Like all older people, (pt) can get acutely sick. When that happens, you might need to decide whether to send him/her to the hospital.**
- > **In general, the hospital can be a traumatic and frightening place for people with advanced dementia. This may be the case for (pt). Being cared for by unfamiliar people can be scary for him/her.**
- > **It is important to consider whether going to the hospital can meet the main goal for (pt).**

- > **Anticipatory guidance**



Referring to Palliative Care

- > **Secondary/Tertiary Palliative Care**
- > **Challenging symptom management**
- > **Challenging family dynamics**
- > **Help with cultural considerations that might need more time or the aid of interprofessional clinicians**
- > **Palliative care is a medical specialty that provides information, emotional and spiritual support as you and your family work to think about what's most important moving forward. Specialists can help you understand the prognosis and treatment options. The team can help you with difficult decisions if you are undecided or if there are disagreements within your family.**

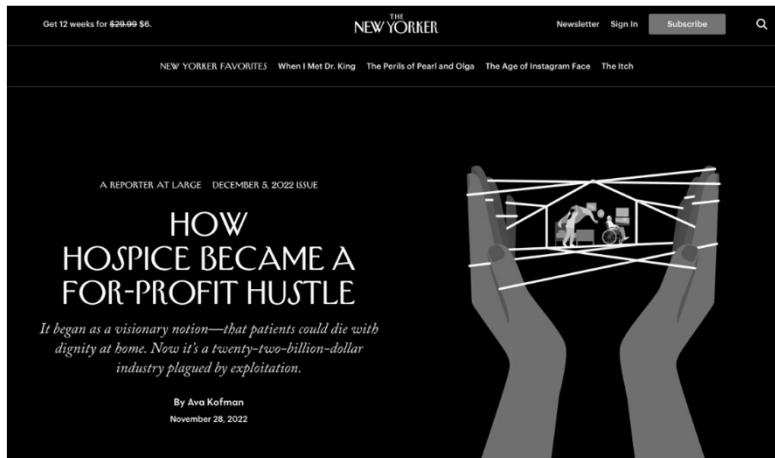


Referring to Hospice

- > **Hospice provides care to pts who have a terminal illness and who are no longer receiving curative treatments**
- > **All care is focused on achieving the best pt comfort and helping the pt to live as well as possible with the time remaining.**
- > **Hospice provides care to people who have a terminal illness and whose main goal is to live as comfortably as possible with the time remaining. Hospice is for people who no longer plan to return to the hospital for treatment and instead want to focus on remaining comfortable at home (or where they are living). A hospice team—usually a nurse, chaplain, social worker, as well as volunteers and aids will follow (pt). Medications, supplies, and medical equipment to provide the best comfort and quality of life are provided through hospice.**



Quick Aside:



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Quality Hospice Care: What to look for

- > **Prior experience with this hospice?**
- > **How often do members of the interprofessional team visit?**
- > **What information do they provide upfront?**
- > **Hospice Medical Director board certified in Hospice and Palliative Care? Certified in Hospice Medical Directorship?**
- > **For profit?**

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Benefits of Hospice

- > **Interprofessional team (nurses, social work, spiritual care, occupational therapy, pharmacist, aids, volunteers)**
- > **Durable Medical Equipment (DME)**
- > **Medications for symptom control and related to comfort**
- > **24/7 availability (by phone)**
- > **Grief and bereavement services up to 1 year following death**



What is NOT provided/covered

- > **Custodial care**
 - Family, friends, hired caregivers must provide care
 - Long-term care facility (SNF, AFH, ALF)
- > **Medications/Treatments with goal of life-prolongation or recovery (eg chemotherapy)**



Functional Assessment Staging Tool (for Alzheimer's Disease)

- > **First developed 1984 by Dr. Barry Reisberg**
- > **Meant to be used for Alzheimer's Disease**
- > **Lowest consecutive score, do not skip levels**



Stage	Functional Assessment Staging Tool (FAST)
1	No difficulties, either subjectively or objectively.
2	Complains of forgetting location of objects; subjective word finding difficulties only.
3	Decreased job functioning evident to coworkers; difficulty in traveling to new locations.
4	Decreased ability to perform complex tasks (e.g. planning dinner for guests; handling finances; marketing).
5	Requires assistance in choosing proper clothing for the season or occasion.
6a	Difficulty putting clothing on properly without assistance.
6b	Unable to bathe properly; may develop fear of bather. Will usually require assistance adjusting bath water temperature.
6c	Inability to handle mechanics of toileting (i.e. forgets to flush; doesn't wipe properly).
6d	Urinary incontinence, occasional or more frequent.
6e	Fecal incontinence, occasional or more frequent.
7a	Ability to speak limited to about half a dozen words in an average day.
7b	Intelligible vocabulary limited to a single word in an average day.
7c	Non-ambulatory (unable to walk without assistance).
7d	Unable to sit up independently.
7e	Unable to smile.
7f	Unable to hold head up.



Hospice Criteria for (Alzheimer's) Dementia

FAST 7c plus one of the following within the past 12 months:

- **Aspiration pneumonia**
- **Pyelonephritis**
- **Septicemia**
- **Decubitus ulcers, multiple, stage 3-4**
- **Fever, recurrent after antibiotics**
- **Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous 6 months or serum albumin <2.5 gm/dL**



Implications

- > **Patients can't qualify for hospice services until they are quite debilitated (non-ambulatory)**
- > **Care needs will already be significant (full-time, 24-hr care)**



Palliative Care Communication Pearls:

- > **Ask permission (a lot) – Allows some control back in situations where illness can feel like it has taken away all control**
 - Also acts as a mild warning sign and allows pt/proxy to avoid topics they might not feel emotionally or psychologically prepared to navigate
- > **Respond to emotion (NURSES)**
 - Naming
 - Understanding
 - Respect
 - Supporting
 - Exploring
 - Silence



Palliative Care Communication Pearls:

- > **Don't assume you understand vague statements**
 - You can always clarify
 - Or ask an open-ended question
- > **Wish/Wonder/Worry:**
 - I wish... (align)
 - I wonder... (respectful curiosity/exploring further)
 - Can I share with you a worry that I have? (presenting our concerns in the face of prognostic discordance)
- > **A lot of these strategies aim to provide a psychologically safe space to engage in potentially stressful conversations**



Cultural Considerations:

- > In cultures in which talking about a pt's future could bring about that future, consider using examples:
 - For many people with advanced dementia...
 - For some families caring for a family member with advanced dementia...
 - Ask about examples from their own experiences:
 - > Has anyone you've known had dementia?
- > **EthnoMed free and wonderful resource**
 - <https://ethnomed.org/>



Case:

Mrs. S is an 87 yo woman you have been treating for 10 years. She was diagnosed with dementia (likely Alzheimer's) 4 years ago and was doing well at her memory care facility (able to ambulate independently, attending activities, has bladder incontinence and needs help w/ dressing, bathing, and toileting), but recently had a fall and was hospitalized w/ a hip fracture, now s/p ORIF and SNF for subacute rehab. She is brought in by her daughter who is concerned that her mom did not recover to her pre-hospital baseline and is now in bed for half the day, attends/participates in fewer activities, and is no longer able to feed herself. You had not previously discussed advanced dementia with her daughter and are not sure what her daughter knows about the course of dementia.



Case Continued:

- > **What are you hoping to discuss with Mrs. S's daughter today? Topics you might want to touch on?**
- > **After greetings, think about what you want to say or ask. What would you say/ask to open up this conversation or introduce your topic?**



Case Continued:

You have a telehealth appointment today with Mrs. S and her daughter Jane. The memory care facility Mrs. S lives in helped set up a video conference. Jane is concerned since the memory care staff report that Mrs. Smith no longer seems interested in food (previously she had enjoyed meal times) and has lost 4 pounds over the last month. During your last visit several months ago, you made good progress introducing the idea of advanced dementia as a terminal illness but did not get into details about eating problems, hospitalization, and infections. Jane was teary when discussing advanced dementia, but felt she needed time to talk to her two brothers (Mrs. S's sons) about what their mom might prioritize.



Case Continued:

- > **What might you want to attempt to cover today?**
- > **What questions do you have for Jane since last visit?**
- > **Think about how you want to approach today's visit. What are you going to say/ask in order to start today's discussion?**



Case Continued:

Same case, except Jane and her mother are Somalian. Instead of being cared for in a memory care facility, Jane has been caring for her mother at home by herself. Jane has older brothers who frequently check in and can watch Mrs. S if Jane needs to run out for groceries or errands, but Jane does the majority of primary caregiving. After your last visit, Jane and her brothers decided that they wanted to prioritize longevity for their mother who worked hard to raise and support them when they were young. Jane and her brothers are very concerned that Mrs. S is eating less, sleeping more, and losing weight.



Case Continued:

- > **What might you want to attempt to cover today?**
- > **What questions do you have for Jane since last visit?**
- > **Think about how you want to approach today's visit. What are you going to say/ask in order to start today's discussion?**



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Questions?

THANK YOU!