Chapter 7

Frailty, Resilience, and Palliative Care Considerations for those Living with Dementia

Maureen C. Nash

Dementia as a Chronic Life-Limiting Illness

Dementia is a chronic illness, often lasting for the last one to two decades of a person's life. Most types of dementia are progressive, a condition in which neurons in the brain stop functioning and die over time, leaving neurologically induced cognitive, emotional, and behavioral deficits. This is analogous to congestive heart failure where cardiac cells die or stop functioning and the heart loses the ability to pump blood efficiently. These similarities have led many to conceptualize dementia as a form of chronic brain failure.

One reason for the paradigm shift of viewing dementia as chronic brain failure is to enable better planning over the entire course of illness. However, having a terminal condition is not the primary thing to know about someone living with dementia and need not be the defining fact of a person's life. Understanding the progressive nature of dementia, it is essential to learn a person's habits and preferences as early on as is possible. This

---

M. C. Nash (✉)
School of Medicine, Oregon Health and Sciences University,
Portland, OR, USA

Providence ElderPlace Oregon, Portland, OR, USA

M. Nash, S. Foidel (eds.), *Neurocognitive Behavioral Disorders*, https://doi.org/10.1007/978-3-030-11268-4_7

can then be combined from what is learned through regularly reassessing a person's abilities with objective functional cognition tests. Person-directed care is the ideal. When that is not possible, person-centered care can be led by those who know the person best. In this chapter the history of the movement to transform dementia care to person-centered and person-directed care is reviewed. Next, frailty and resiliency are reviewed in the context of dementia. It is essential to clarify and update the goals of care throughout the course of the illness. To palliate is to focus on decreasing suffering and therefore encouraging use of the palliative care model is reviewed. Dementia as a terminal illness will conclude the chapter.

The "D" Word

There is significant stigma associated with the word dementia. *The D word*, dementia, follows in the footsteps of the *C word*, cancer. In the 1950s and 1960s, people spoke of the C word when referring to cancer. Cancer was considered an automatic death sentence. There were few treatments available, and those available often caused horrifying side effects and functional decline, with a successful treatment rate of less than 33% [1]. In Britain, a debate raged over whether to educate the lay public about cancer at all and the experts, at the time, voted against education. Fear and dread surrounded the topic and even the word. Compared to today, cancer was poorly understood. Previously cancer was seen as a monolithic entity. Only in the past few decades have the etiology, prognosis, and treatment for hundreds of distinct types of cancer been understood [2]. Radiation and surgery were the mainstays of treatment, and survival rates were low. Though radiation and surgery may stop some forms of cancer, their efficacy was marginal in decreasing mortality, and the physical toll of treatment was great, at times inflicting suffering considered worse than the original disease. It was not just controversial to educate the public at large about cancer but even to tell people of their own diagnosis [3]. Gilbertsen and Wangensteen presented a 1961 paper "Should the Doctor Tell the Patient that the Disease is Cancer?" presenting objective data that a large majority of people with cancer wished to be told of the diagnosis. At the time, a debate occurred in medical circles about informing people of what was known about their diseases…cancer came to be known as "the C word." In Britain, the decision was to withhold the diagnosis of cancer from the person [4, 5].

The modern idea of informed consent, explaining the diagnosis, risks and benefits of various treatments in person-centered language, including no treatment, emerged quite slowly in the medical world. A similar revolution in the diagnosis of dementia syndromes is now emerging. Healthcare professionals remain reluctant to give the diagnosis of dementia. In 2015 physicians who diagnosed someone with dementia disclosed this to them less than 50% of the time [6]. This lack of disclosure may partially be explained by the current lack of disease modifying treatments. The history regarding diagnosis and treatment of cancer is reviewed because the same ethical discussions are being repeated and lessons re-learned in the present day about dementia.

The term dementia encompasses multiple syndromes as outlined in earlier chapters. But in the public mind, a single syndrome of dementia exists. This is repeatedly seen in books written for the public, as well as some written for healthcare providers. People dread hearing a diagnosis of dementia for themselves and those they care about. Sometimes the dread is more specific: "It is OK if I have dementia as long as it isn't Alzheimer's." This belies the reality that the vast majority of those with dementia do have Alzheimer's disease or Alzheimer's plus a second type of dementia [7].

Transitioning to Person-Centered and Person-Directed Care

In the 1980s, a movement, sometimes labeled the culture change movement, was started by a few providers, advocates, regulators, and caregivers in nursing homes. This movement emphasized shifting care of persons living with dementia away from an institutional and regulatory focus to an individual person-centered focus. One example of this paradigm shift was simply knowing what time the person likes to get up in the morning and adjusting the care setting's practices and policies to meet the individual's needs and desires. At the time this was a revolutionary concept in most care settings. Many a rocky start to the morning for resistive residents was resolved by allowing people to sleep in and awaken on their own schedule. Organizations that worked to this end include the Pioneer Network, the Eden Alternative, and others. One approach, the *Best Friend*s model outlines the rights those living with dementia have and what elements of a person's life story are important to know [8]. There are many other organizations that now share this same mission. The focus is on a personal and respectful relationship between person and caregiver. This is especially important for paid caregivers. However, even in the case of family or friend caregivers, a thorough review of information about a person's life is recommended especially those segments prior to knowing family or caregivers. Spouses are sometimes surprised to learn childhood details, while siblings and childhood friends at times have less knowledge about a person in their adult life. The premise of the Best Friends model is to treat people living with dementia as one would treat a friend, knowing likes, preferences, and style. Knowing the person's life story is one important tool to assist them in a personal and meaningful way. Moving to the next step in problem solving and care planning is much more easily and individually accomplished when a person's personal and cultural history is understood [8]. It remains important to maintain solid professional boundaries even when using this Best Friends approach toward caregiving of vulnerable older adults because the power differential inherent in a caregiving relationship precludes actual friendship. Those who only hear about the Best Friends approach without understanding the context may be more susceptible to boundary violations.

The Eden Alternative continued to expand the culture change movement. The Eden Alternative philosophy began in 1991 when an emergency department physician found himself as the medical director of a nursing home. He came to view aging and working with those who found their home to be a nursing facility in a whole new light. He determined that the three most serious challenges for those living in nursing homes, including those living with dementia, were not their medical problems or nursing needs but rather, loneliness, helplessness, and boredom [9]. The culture change embodied by the Eden Alternative, the Best Friends approach, and other culture change traditions continues to be reinforced and enlarged by the Pioneer Network and other organizations [10].

There is a new emphasis by some leaders in the medical field to focus on the positive aspects of living with dementia. The rationale for this movement is centered in concerns that respect and dignity for people, including those who have dementia, have been lost and there is a need to focus not on what people cannot do but on those things a person can do. This is called "the positive approach to dementia care." Dr. Power and others postulate that the distress seen in people with dementia is not due to the dementing process itself but instead due to a state of compromised well-being. He and others emphasize person-directed and strength-based care. The movement referred to as a positive approach is contrasted with an approach that focuses on the decline and death that accompany advancing dementia [11]. Some have expressed significant concerns on a shift away from research supporting those with dementia, as they lose functioning, to promote personhood. It is vital to respect people living with dementia and let them direct care whenever possible as well as focus on abilities and support all efforts toward resiliency. It should not prevent a parallel focus on the prognosis of dementia and preparing for the end of life. It is vital to plan with and for the future needs of people while always keeping the person and personhood of those living with dementia at the center [12].

Frailty and Resilience

Frailty is a term that is often used by caregivers to describe older adults who are frequently tired or isolated. Formally, frailty is difficult to define precisely. Frail older adults can be described as those who have increased vulnerability to loss of function and debility while having decreasing ability to resist illness. Definitions of frailty vary; some including psychosocial factors and other definitions generally include weight loss, fatigue, low muscle mass/weakness, slowed physical abilities, and low physical activity [13]. The literature describes frailty as a multisystem decline in which older adults are more vulnerable to falls, fractures, and infections. Typically, the organ systems most impacted by frailty are the immune, skeletal, endocrine, and neurological. Those who are frail are increasingly vulnerable to minor changes to their environment [14] (Table 7.1).

Included in frailty is the idea of a *frail brain*, in which frail older adults are more vulnerable to quickly developing delirium. In a simplified model of the frail brain, although structures may not be detectably altered, the metabolic efficiency of neural networks is decreased. The frail brain has less efficiency or resistance to changes such as introducing new medication, infection, and malnutrition [14]. This model of functional brain decline, even though structurally the brain

Table 7.1 Examples of common symptoms of frailty and associated functional deficits

Symptom of frailty	**Functional outcome**
Decreased muscle mass	Frequent falls
Generalized weakness	Fear of falling; high fall risk
Low grip strength	Decreased participation out of residence
Fatigue	Increased isolation; decreased participation
Malnutrition	Increased fractures, increased fatigue
Decreased immune system	Frequent infections
Decreased mobility	Increased isolation; infections and skin breakdown risk

appears unchanged, may explain why functional medical imaging such as PET scans can aide diagnosis of dementia while CT scans and standard MRIs are of far less assistance [15]. Many clinicians increasingly theorize that functional cognitive impairment and frailty occur hand in hand. Impairment in cognition is a central feature of frailty for many older adults. Dementia, coupled with frailty, is a strong predictor of mortality [16]. Identifying individuals who meet the definition of frailty can assist in planning for their care. Preventive care planning for frail elders may include strengthening programs, nutritional support, frequent social interactions, cognitive stimulation, and referrals to skilled therapy for either maintenance or restorative therapy [17].

Frailty is sometimes juxtaposed against resilience. The medical model focusses on the decline of functioning to define older adults rather than using a focus on person-centered care to increase resiliency in older adults. Older adults, significantly more than younger adults, emphasize positive coping with what functional limitations one has rather than a focus limited to reversing physical declines. Older adults are more likely to recognize that reversing physical declines may or may not be possible. This is the nature of resilience. Resilience is not the lack of frailty but rather coping with it in a positive manner. Other elements of resilience in the social sphere include working to improve or change societal ills including supporting the environment, fighting economic inequality, working toward a sustainable future, fighting sexism and racism, as well as preserving earth's finite resources by living simply. Actively supporting good works in society can be an antidote to succumbing to fatigue and loneliness. Successful living in a resilient manner also includes recognition of death as a part of life-successful aging includes successful dying. One key here is working to preserve personal choice and dignity during the final phases of life. It is hypothesized that this is part of the generalized dread of ending up living in an institution. For those with dementia, maintaining control and choice requires active planning early on in the course of the disease [18, 19].

Successful, resilient aging: coping with decline.

Maintaining dignity through a focus on personal agency, social value and quality of one's life as well as the quality of one's death.

(A compilation of the sentiments expressed by older adults in Mortimer, 2008)

Care Conversations as a Central Organizing Strategy

The medical model in the United States centers around acute care. This does not serve those with significant chronic illness very well. When the focus is on the current crisis, understanding and planning for the whole trajectory of disease is easily lost. When one has cancer, there is a focus on maintaining wellness and quality of life, but no one suggests ignoring the life-threatening aspects of that illness. Because the brain is intimately involved in all our emotions, behaviors, and communication, it is essential that we recognize the suffering involved when parts of the brain are not working. In incorporating components of a wellness model, one still needs to acknowledge the larger realities of the underlying disease. Part of honoring the dignity of the person is recognizing personal suffering. Absolutely every person is worthy of dignity and respect including people with neurodegenerative illness. When the discussion turns to caregiver education, it often centers on supporting functioning or decreasing distress of the person with dementia. However, there is a real deficit around education of prognosis and what the end of life looks like for people as dementia advances.

Increasingly we are encouraging frequent goals of care discussions with those who have dementia in the earliest stages of their illness and updating goals as the disease advances. In this way, healthcare decision-makers will have an accurate understanding of what a person values in life, as well as what type of death is unacceptable to that person. By helping to focus on what a person's goals are in the context of knowledge about disease progression, we are much more likely to achieve a palliative approach and decrease suffering over time [20]. Caringkind is an organization in New York City dedicated to education and support for those with Alzheimer's disease and other dementias. After completing a 2012 pilot project around supporting those with dementia as they near the end of life, they developed some guidelines published in a booklet [21]. This is an active area that many organizations are beginning to focus on. There is a strong sense that these goals of care conversations and subsequent palliative care belong in the primary care environment and that those who work in long-term care need to be aware of this information.

When people think about dying, often the model is around cancer where the decline lasts a few months to days or even hours. Figure 7.1 is the common trajectory when one has cancer. Functional capacity is often preserved until near the very end of life.

This is in sharp contrast to the trajectory of functional decline seen in those with major neurocognitive disorder. This has been best researched and described for Alzheimer's disease where the decline is more akin to the example in Fig. 7.2. Drawing this type of diagram during a family meeting can be extremely helpful in explaining where a person in the trajectory of their disease and their life.

Allowing time to discuss the future throughout the illness is important. More than 50% of people in the United States

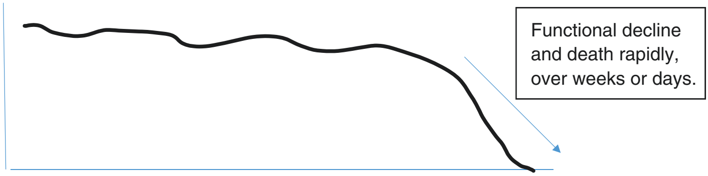


FIGURE 7.1 Trajectory of life and death with cancer. (Original figure created by Maureen C. Nash, 2017, Copyright Maureen Nash, MD)

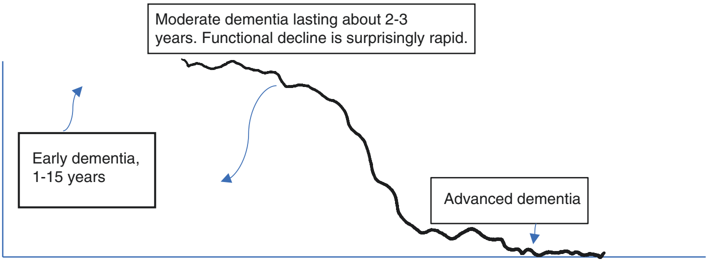


FIGURE 7.2 Trajectory of life and death with Alzheimer's disease. (Original figure created by Maureen C. Nash, 2017, Copyright Maureen Nash, MD)

express a wish to die at home when possible [22]. It is important to remember that the choice isn't about whether death will occur. All living humans die. The choice is about focusing on the quality of life, and the values of the person before the dying process are imminent and while they can discuss their wishes. This is the time to review the link between hospitalizations and permanent functional decline and worsening of cognition experienced by those with dementia [23, 24]. This is a key time to discuss what types of events for which a person would want to be hospitalized, when would they want to consider CPR, and when would they prefer to allow natural death to occur. Generally older adults recognize that life will end and death is not optional. It is often the family of an older adult which finds this concept more challenging to accept. This is one reason it is recommended that family members be included in discussions preparing for the entire course of dementia in addition to the person diagnosed with dementia. Goals of care and what is considered a desirable quality of life are dependent on where along the trajectory of disease one currently is as well as long-standing philosophical and spiritual beliefs.

One common model is to focus on longevity of life prior to the development of a life-limiting disease such as dementia. After the diagnosis, at some point, the focus often shifts to maintaining the highest level of day-to-day functioning that is possible. Once advanced dementia occurs, many choose to focus on comfort and palliation of suffering. If people with dementia are not afforded the opportunity to discuss this early in their illness, their family and healthcare providers may not be able to discuss it with them later in the illness. The content of these discussions needs to be adjusted to the values of the person living with dementia. Also, if the type of major neurocognitive disorder is not Alzheimer's disease, it may have a different trajectory. However, this model of adopting a longitudinal view of the course of disease progression offers those who want to express their wishes the ability to do so [20]. For those with dementia, advanced directive discussions and possibly other documents should address the use of feeding tubes, as well as the use of antibiotics and hospitalization when the goals of care are comfort and the decrease of suffering. There is a significant body of evidence showing that feeding tubes do not prolong life in those with advanced dementia, rather they lead to more invasive medical procedures and infections without a benefit of fewer cases of pneumonia and other negative medical sequelae [25].

The Conversation Project is an online website that has downloadable conversation starter kits at theconversationproject.org

They also have a free course to assist people in having these discussions about end-of-life care. The website also has other resources about advanced care planning.

Palliative Care

This emphasis on early and robust discussion of goals of care is important for those with dementia before the disease advances to the final stages. The time to begin considering palliation or relief of suffering is at the time of diagnosis of any serious illness, including dementia. Whether one is diagnosed with cancer, congestive heart failure, or dementia, it is never too early to look to palliate symptoms. Palliative care involves a focus on relief of suffering and addressing symptoms that impair quality of life. This supports a dignified approach to respecting the personhood of those with dementia while not denying the terminal prognosis that this illness portends. There is concern that the positive approach to the terminal disease of dementia carries a risk of denying the suffering that clearly occurs both in people with dementia and in those who care for them. This does not have to be a binary choice; one can focus on well-being even as one addresses the larger issues around prognosis [12].

Terminal Diagnosis –
what are the person's goals of care?

Aggressive Medical Management/Disease Modifying Treatment	• Options not present • Communication is restricted by a curative only approach to diagnosis
Transition from Disease Modifying to symptom management	• Allows communication about prognosis and care options • Establishes proactive experiences through open awareness • Affords patients and families opportunities to experience end-of-life care preferences • Discussion of advanced directives
Palliative Care: Holistic, symptoms management focused	• Discussion of disease progression, individualized plans of care and advanced directives • Early communication assists in implementation of palliative care • Provide knowledge, characterized by open awareness and focus on quality not quantity of life

Most major neurocognitive disorders are complex progressive neurodegenerative illnesses that lead to a person's death. According to the Alzheimer's Association in 2018 [26], Alzheimer's disease is a top 5 cause of death among older adults. Until recently, there have been few studies in the medical literature about the quality of life and quality of death in people with dementia. Slowly this has been changing over time. In an article published in 2004, Sachs et al. [27] studied how persons with dementia were dying. They found that there was inadequate pain control and many people with dementia were dying with feeding tubes in place despite no benefit to the person who had it. Generally, people did not have the benefits of palliative or hospice care. Over time, in some states those with dementia have moved out of nursing homes and into specialized assisted living facilities or memory care units. A sobering study published in 2014 found that, despite 20 years of education and discussion of the links between pain and dementia, pain was still routinely undetected and misinterpreted in people with dementia [28]. Some positive improvements noted were pain being considered when people were calling out or were grimacing, wincing, moaning, or frowning. There was some mention of pain when staff noted pacing and restlessness. However, screaming and aggression did not lead to consideration of pain. Most pain medications were given as needed even though those with advanced dementia are the least likely to be able to verbally indicate a need, and thus staff must interpret behaviors. There remains resistance to using opiate medications among many staff members because of the concern for safety. Finally, few interventions were described for the common challenge when people with dementia are refusing medications [28].

The National Institutes of Health supported the choices, attitudes, and strategies for care of advanced dementia at the end of life (CASCADE) study in 22 nursing facilities [29]. They found the pattern of symptoms in those with dementia were quite similar to other terminal illnesses such as cancer. This is one of a number of more recent attempts to collect data so that we can shift our outlook and implement appropriate treatment for those with dementia. Results of the CASCADE study, published in 2009, indicated that those with advanced dementia near death suffered significant infections and eating problems. They also found that distressing symptoms likely to cause suffering were common and increased as death approached. Many of those with advanced dementia underwent burdensome interventions that were unlikely to benefit them or improve the quality of life of their lives. Survival was poor after the development of eating problems or infections. One major care variable was how aware the healthcare proxy was of the poor prognosis of the person with dementia. Less than one in five healthcare proxies stated that they had received prognostic information from a physician. Only one in three healthcare proxies reported that a physician had counseled them about likely complications as death neared. Of the residents with dementia who died, three in ten received hospice referrals. Some of the more distressing symptoms experienced during the last few months of life included significant dyspnea, pain, pressure ulcers, aspiration, and agitation [30].

Palliative care is often confused with hospice care. Hospice care involves palliation of symptoms and suffering; thus, it encompasses palliative care. Hospice itself is a defined insurance benefit designed to support people in the final phase of a terminal illness, defined as the last 6 months of life. However, palliative care focusses on prevention and relief of suffering in all settings. It is not limited only to a hospice setting nor only to those in the last few months of life. One of the challenges with hospice care in the past has been that it is modeled on the way terminal cancer progresses. Often when we treat someone with terminal cancer, there is a period of very aggressive medical care, and then once it appears that there will be no further benefit, this care ceases and is rapidly followed by decline and death. Dementia and frailty, on the other hand, are syndromes where over time medical interventions are used less and less because they're effectiveness is noted to be poor. For those with dementia or frailty, it is significantly more difficult to give families and caregivers an exact prognosis. The National Hospice and Palliative Care Organization recommends the Functional Assessment STaging for Alzheimer's/Dementia (FAST) criteria to qualify people with dementia for hospice. FAST scores range from 1 to 7 where those with the lowest scores are the most functional. Typically, a score of 6 or 7 is utilized to qualify for the hospice Medicare benefit.

Stage 7 on the FAST scale

- 7a Person uses less than 6 meaningful words per day
- 7b Person uses one or fewer intelligible word in any average day
- 7c Person has become unable to walk without assistance

One challenge with the FAST scale is that there are many reasons why a person may be unable to walk without assistance that have little to do with their dementia. In 2004, it was found that the FAST criteria generally did not accurately predict 6-month survival for those with dementia. The FAST criteria were not derived from empirical data of people who had dementia. In one study 7 out of 10 people who reached stage 7C in a stepwise fashion by first reaching stage 7A and then 7B did die within the 6-month window expected for hospice qualification. However, for those who reached stage 7C but did not travel through stage 7A and 7B, only three out of ten died within 6 months of enrollment with a median survival of nearly 11 months. In other words, for those who did not progress in a stepwise fashion, 70% of people with dementia live longer than 11 months. For those living in nursing homes, a model has been developed from the minimum data set (MDS). This model looks at ADL dependence, being bedbound, incontinent of bowel, having significant symptoms or illnesses such as cancer, congestive heart failure (CHF), oxygen dependence or dyspnea, medical instability, eating less than one quarter of all meals, sleeping most of the day, being male, and age to greater than 83. A score using this combination of factors was found to predict mortality for those people living with dementia in a nursing home [31].

A group of physicians in a palliative care unit for those with dementia and difficult to control symptoms developed a simpler too to measure suffering in those with end-stage dementia, the Mini Suffering State Examination (MSSE). The Mini Suffering State Exam consists of ten yes or no questions. These questions are designed to correlate with the concept of suffering in those with advanced dementia [32–34].

Criteria found on the Mini Suffering State Exam (Copyright Bechor Zvi Aminoff, Mini Suffering State Examination, 1999, Gerontologie und Geriatrie. Volume: 32, 2. p. 238).

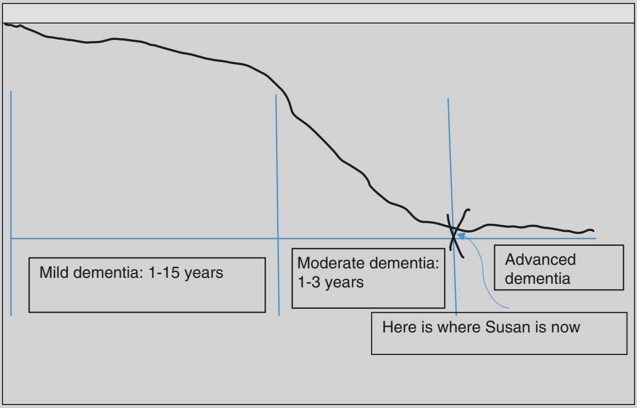
1. Calm? level of calmness of the person with dementia
2. Screaming or calling out?
   Pain especially as evidenced by nonverbal indications?
3. Presence of decubitus ulcers?
4. Malnutrition?
5. Eating disorders as measured by refusals to eat, dysphagia, anorexia or a feeding tube?
6. Need for invasive action such as frequent blood tests, urinary catheterizations, IV or subcutaneous fluids, blood transfusions, dialysis etc.?
7. Acute medical condition such as pneumonia, urosepsis or electrolyte imbalance in the last few months of life?
8. Suffering in the opinion of the medical provider or nursing staff?
9. Suffering in the opinion of the family?

A study published in 2006 found that the MSSE predicts 6 months or less to live when it indicated an elevated level of suffering as evidence by a score of 7–10. The Mini Suffering State Exam is well received by family members and staff. It has been shown in studies to be one of the most usable scales to administer in a clinical setting [35].

Case Study: Susan

Susan had become suspicious that others were stealing from her. This was accompanied by loud yelling and threatening random people who came up to her. She had no past psychiatric history of paranoia or delusions, but these were apparent upon assessment. She developed these same concerns about new people she met, as well as those she recognized. She herself was only oriented to person and could give no accurate recent information. History showed that she had been seen in the ED for a fever and found to have an infected pressure ulcer. She was losing weight and had a very low albumin and total cholesterol. She was using a wheel chair most of the time. She could stand and bear weight but appeared to be apathetic towards walking and did not spontaneously try to get up. Her neuropsychiatric symptoms responded to a combination of environmental support and medications. She was still being treated with warfarin for long-standing atrial fibrillation requiring frequent lab draws especially as her oral intake remained varied. Her family thought she was suffering as did her primary care provider. Her Mini Suffering State Exam score was 7. Because she was still verbally interactive her family was very surprised to hear that she was at high risk of death from the advanced dementia.

Occupational Therapy had seen Susan for an evaluation. Her Allen Cognitive Level was 3.2. This is consistent with severe functional impairment. Someone functioning at this level needs 24-hour supervision, consistent routines are recommended. Communication requires clear and concise statements. Eating, dressing, hygiene, toileting require cueing, assistance and supervision. The drawing below was shared with Susan's family during an office visit.



After this discussion, the family decided to pursue a palliative care pathway. Routine lab draws were stopped, Susan was offered finger foods meeting her past preferences. All medications that were unlikely to add to her quality of life over the next year were stopped. She became slightly less apathetic after 4 cardiac medications were stopped. Approximately 4 months after this assessment, Susan died in her sleep in her daughter's house.

- Physicians and other healthcare professionals should consider palliative care at the time of diagnosis of any serious chronic illness, including dementia.
- Discussions around goals of care need to be honest and open, with periodic updates as life progresses.
- Increasing frailty and promoting resiliency can coexist.
- Education and support are essential for family and all caregivers.

- Treat the person, not the symptom.
- Advanced Dementia is a progressive, terminal illness.
- Quality of life includes engagement in meaningful activity, connection with others including caregivers, and controlled pain.

References

1. DeVita VT, Chu E. A history of cancer chmeotherapy. Cancer Res. 2008;68(21):8643–53.
2. The National Cancer Institute, Mission Statement. https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-cancer-institute-nci. Last Accessed 25 Nov 2018.
3. Toon E. "Cancer as the general population knows it": knowledge, fear, and lay education in 1950s Britain. Bull Hist Med. 2007;81(1):116–38.
4. "Cancer as the general population knows it": knowledge, fear, and lay education in 1950s Britain. Bull Hist Med. 2007;81(1):116–38.
5. Gilbertsen VA, Wangensteen OH. Should the doctor tell the patient that the disease is cancer? CA Cancer J Clin. 1962;12:82–6.
6. Alzheimer's Association. 2015 Alzheimer's disease facts and figures. Alzheimers Dement. 2015;11(3):332–84.
7. Nash MC, Foidel S, Shindler M. Practical assessment and management of behavior disturbance in patients with moderate to severe dementia. Course at the annual meeting of the American Psychiatric Association, Atlanta, 2016.
8. Troxel D, Bell V. The best friends staff: building a culture of care in Alzheimer's programs. Baltimore: Heath Professionals Press; 2001.
9. Thomas WH. The Eden alternative: nature, hope and nursing homes. Columbia: University of Missouri Press; 1994.
10. The Eden Alternative: Mission, Vision and values. http://www.edenalt.org/about-the-eden-alternative/mission-vision-values/.
11. Power GA. Dementia beyond disease: enhancing wellbeing. Baltimore: Health Professions Press; 2014.
12. Hyden L, Lindemann H, Brockmeier J. Beyond loss: dementia, identity and personhood. Oxford: Oxford University Press; 2014.

13. Collard R, Boter H, Schoevers R, Oude Voshaar R. Prevalence of frailty in community-dwelling older persons: a systematic review. J Am Geriatr Soc. 2012;60:1487–92.
14. Clegg A, Young J, Iliffe S, Rikkert MO, Rockwood K. Frailty in elderly people. Lancet. 2013;381(9868):752–62.
15. Ishii K. PET approaches for diagnosis of dementia. Am J Neuroradiol. 2014;35(11):2030–8. https://doi.org/10.3174/ajnr.A3695.
16. Kulmala J, Nykanen I, Manty M, Hartikainen S. Association between frailty and dementia: a population-based study. Gerontology. 2014;60(1):16–21.
17. Tazkarji B, Lam R, Lee S, Meiyappan S. Approach to preventive care in the elderly. Can Fam Physician. 2016;62(9):717–21.
18. Jeste DV, Savla GN, Thompson WK, Vahia IV, Glorioso DK, Martin AS, Palmer BW, Rock D, Golshan S, Kraemer HC, Depp CA. Association between older age and more successful aging: critical role of resilience and depression. Am J Psychiatry. 2013;170:188–96.
19. Mortimer PM, Ward L, Winefield H. Successful ageing by whose definition? Views of older, spiritually affiliated women. Australas J Ageing. 2008;27(4):200–4. https://doi.org/10.1111/j.1741-6612.2008.00305.x.
20. Murray SA, Kendall M, Boyd B, Sheikh A. Illness trajectories and palliative care. BMJ. 2005;330(7498):1007–11.
21. CaringKind, The Heart of Alzheimer's Caregiving (2016). Palliative care for people with dementia: why comfort matters in long-term care. https://www.caringkindnyc.org/palliativecare/. Accessed 2/4/2019.
22. Institute of Medicine. Improving quality and honoring individual preferences near the end of life. Washington, DC: National Academy Press; 2015.
23. Covinsky KE, Palmer RM, Fortinsky RH, et al. Loss of independence in activities of daily living in older adults hospitalized with medical illnesses: increased vulnerability with age. JAGS. 2003;51:451–8.
24. Pedone C, Ercolani S, Catani M, Maggio D, Ruggiero C, Quartesan R, Senin U, Mecocci P, Cherubini A. Elderly patients with cognitive impairment have a high risk for functional decline during hospitalization: the GIFA Study. J Gerontol. 2005;60:1576–80.
25. Stewart JT, Schultz SK. Palliative care for dementia. Psychiatr Clin North Am. 2018;41:141–51.

26. Alzheimer's Association. 2018. 2018 Facts and figures. https://www.alz.org/alzheimers-dementia/facts-figures.
27. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. J Gen Intern Med. 2004;19(10):1057–63.
28. Peisah C, et al. Silent and suffering: a pilot study exploring gaps between theory and practice in pain management for people with severe dementia in residential aged care facilities. Clin Interv Aging. 2014;9:1767–74.
29. Mitchell SL, Kiely DK, Jones RN, Prigerson H, Volicer L, Teno JM. Advanced dementia research in the nursing home: the CASCADE study. Alzheimer Dis Assoc Disord. 2006;20(3):166–75.
30. Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, et al. The clinical course of advanced dementia. N Engl J Med. 2009;361(16):1529–38. https://doi.org/10.1056/NEJMoa0902234.
31. Mitchell SL, Kiely DK, Hamel MB, Park PS, Morris JN, Fries BE. Estimating prognosis for nursing home residents with advanced dementia. JAMA. 2004;291:2734–40.
32. Aminoff BZ. Mini suffering state examination. Gerontologie und Geriatrie. 1999;32(2):238.
33. Aminoff, et al. Arch Gerontol Geriatr. 2004;38:123–30.
34. Aminoff BZ, Adunsky A. Their last 6 months: suffering & survival of end stage dementia pts. Age Aging. 2006:597–601.
35. van Soest-Poortvliet MC, et al. Selecting the best instruments to measure quality of end-of-life care and quality of dying in long term care. J Am Med Dir Assoc. 2013;14(3):179–86.