Feeding a Person With Advanced Alzheimer's Disease

An Update

Margaret Clifton, DO William Miller Johnstone, III, PhD, MD Kathryn M. Kolasa, PhD, RDN, LDN

We update our 2011 discussion of feeding the person with late-stage or advanced Alzheimer's disease (advanced AD). We present a case of a 92-year-old woman diagnosed with AD, from our family medicine practice who was brought to the emergency department with fever and a change in mental status. Previously, neither she nor her family had received counseling about the typical trajectory of AD, nor had she made end-of-life plans. We present a discussion of the typical trajectory of AD, involuntary weight loss, advance care planning related to nutrition, and hydration and alternatives to tube feeding. We added a note describing the initial impact of COVID-19 on care. Nutr Today. 2020;55(5):202–210

RECAP: FEEDING A PERSON WITH ADVANCED ALZHEIMER'S DISEASE

As outlined by our colleagues in 2011 (editor's note: see Lee and Kolasa¹), families of patients with advanced Alzheimer's disease (AD) often face difficult choices. Most patients will reach a point where they are no longer eating or drinking adequately to sustain life, and tube feeding has been initiated. Yet, tube feeding has not been proven to extend length of life, improve nutritional status, or improve quality of life of patients with advanced AD. In 2014, the

Margaret Clifton, DO, is a board-certified family physician. At the time of writing this article, she was a geriatric fellow, Department of Family Medicine, Brody School of Medicine at East Carolina University, Greenville, North Carolina. She is pursuing a fellowship in palliative care at Vidant Medical Center, Greenville.

William Miller Johnstone, III, PhD, MD, is a board-certified family physician and assistant professor and director of the Geriatrics Division, Department of Family Medicine, Brody School of Medicine at East Carolina University, Greenville, North Carolina. At the time of writing this article, he was a geriatric fellow in the same department.

Kathryn M. Kolasa, PhD, RDN, LDN, is professor emeritus, Brody School of Medicine at East Carolina University, Greenville, North Carolina, and contributing editor to *Nutrition Today*.

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Correspondence: Kathryn M. Kolasa, PhD, RDN, LDN, 3080 Dartmouth Dr, Greenville, NC 27858 (kolasaka@ecu.edu).

Copyright © 2020 Wolters Kluwer Health, Inc. All rights reserved. DOI: 10.1097/NT.00000000000430 American Geriatrics Society (AGS) in a position statement on feeding tubes in advanced AD recommended against placing tubes in older adults, but instead suggesting altering the environment and creating patient-centered approaches to hand feeding.² Additionally, the AGS cited evidence that even though the outcomes regarding death and aspiration pneumonia are similar between tube feeding and hand feeding, hand feeding promotes comfort. Even so, many patients continue to undergo placement of feeding tubes. Our colleagues¹ previously suggested that having conversations with families regarding therapeutic goals as well as disease trajectory may help in making an informed decision. In this article, we present an update of the research and our discussion of feeding patients with advanced AD.

In 2014, the American Geriatrics Society (AGS) in a position statement on feeding tubes in advanced AD, recommended against placing tubes in older adults, but instead suggesting altering the environment and creating patient-centered approaches to hand feeding.

CASE PRESENTATION

Mrs D. was a 92-year-old woman who presented to the emergency department from home because of fever and change in mental status. The patient was diagnosed with AD 6 years ago and recently moved in with her daughter. She was previously on an acetylcholinesterase inhibitor, donepezil, and an *N*-methyl-D-aspartate receptor antagonist, memantine, meant to reduce symptoms and manage behaviors. After demonstrating clinical worsening, the AD

medications were discontinued. At baseline, she is interactive and alert, but not oriented. Over the past few days, the family noticed Mrs D. was "not acting like herself." She developed a worsening cough and fever. On presentation, she was unable to answer questions. Mrs D. was tachypneic and febrile. Her white blood count was 23 000 with a left shift, a sign of an active infection. Her chest x-ray showed a right lower lobe consolidation concerning for aspiration pneumonia. Mrs D. was admitted to the inpatient service for an overnight stay and was started on intravenous (IV) antibiotics and fluids. The admitting team ordered a swallow study to fully work up the diagnosis. Mrs D. then failed a bedside speech evaluation performed by nursing staff. A formal swallow evaluation in radiology performed by speech therapy was ordered. Mrs D. was to be NPO, or nothing by mouth, until her swallow evaluation was completed.

Mrs D.'s family was understandably upset and confused as to why their mother could not eat or drink, because she was eating and drinking well prior to the last few weeks. They were not able, however, to provide a diet history. They mention she occasionally coughed when eating and had overall decreased intake of food. They also noted that Mrs D. would hold food in the sides of her mouth that she would not swallow. Additionally, when asked, they said, "Now that you mention it, we think she has lost about 15 lb over the past few months." They were hopeful she would pass the swallow study and return home.

BACKGROUND

Typical Trajectory of AD

The trajectory of AD is characterized by a gradual reduction in cognitive function, leading to complete dependency on caregivers for activities of daily living. One expert suggested the median survival time after diagnosis is 3 to 12 years.³ Another noted the advanced AD lasts from 6 months to 2 years⁴ and is characterized by limited ability to perform basic functions such as speaking, maintaining body posture, and smiling. Although executive function and memory are first affected, patients with AD usually develop the inability to maintain their hydration and nutritional status without intervention. The experts agree that eating difficulties are inevitable.⁵ In 2009, Mitchell et al⁶ provided an often-quoted description of AD as a terminal disease. The article of Mitchell et al⁶ remains the best description of many of AD's features, and we will cite their work when unable to find more recent data. They reported that 86% of patients with advanced AD experience difficulty with oral feeding in the form of loss of interest in eating and/or dysphagia.⁶ Likewise, the incidence of eating problems in patients with AD increases with time in a predictable and gradual fashion (Figure 1) with changes in the care and the intensity of caregiving required at each juncture of the disease. The onset of feeding problems



FIGURE 1. Overall mortality and the cumulative incidences of pneumonia, febrile episodes and eating problems in nursing home residents with advanced dementia. From Mitchell et al.^{6(p1533)} Copyright © 2009. Massachusetts Medical Society. Reprinted with permission from Massachusetts Medical Society.

is, unfortunately, inevitable in the course of AD. Oftentimes, the complications related to aspiration pneumonia characterize advanced AD and ultimately lead to death. As eating problems increase, so do episodes of pneumonia and overall mortality. The appreciation of this relationship is vital to understanding the characteristic trajectory of AD. The 6-month mortality rate for patients with advanced AD and eating problems is 38.6%. Figure 2 illustrates the relationship between the onset of feeding problems and overall survival, and the results are predictable and follow the expected overall trajectory of the disease. Importantly, it is the observable signs of feeding problems and resulting complications, which are most disturbing to caregivers and loved ones, understandably fueling their search for possible mitigating strategies, such as feeding tubes. These authors did not discuss Involuntary Weight Loss (IWL) in their article.6

Alzheimer's dementia follows a predictable and gradual trajectory that will evolve over time.

Using the Functional Assessment and GDS Scales

The FAST (Functional Assessment Scale; Table 1) and GDS (Global Deterioration Scale) are used by healthcare professionals to identify the stages of dementia with a score of 7a indicative of advanced AD.^{7,8} Healthcare professionals often



FIGURE 2. Probability of survival (days) no eating problems/eating problems. From Mitchell et al.^{6(p1534)} Massachusetts Medical Society. Reprinted with permission from Massachusetts Medical Society.

use these scales to monitor a patient's AD as it progresses and to predict life expectancy. Mitchell⁹ demonstrates the use of the FAST to assist family in establishing the goals of care, noting the most common clinical complications requiring management decisions in advanced AD are eating problems and infections.

Involuntary Weight Loss

Other reports expand the discussion of eating problems in advanced AD. It is notable that observations about IWL and interventions to minimize it were made in the mid-1980s. In 2006, Johnson et al¹⁰ concluded that weight loss may be a preclinical indicator of AD. Yet, in 2010, Inelman et al¹¹ noted that researchers were still asking the question: is IWL a cause or a consequence of AD? Using animal models, a neuroscience researcher in 2014 suggested that leptin, an anorexigenic or appetite-inhibiting hormone, might be involved in the development of AD and also the progressive deterioration of the individual with AD.¹² The authors proposed a novel mechanism where leptin resistance, which occurs as a component of the overall metabolic dysregulation seen in obesity, and decreased leptin levels seen in underweight individuals with advanced AD both contribute to impaired brain function and to cognition. Furthermore, they suggested that the characteristic AB (B amyloid) and tau accumulation seen in AD may impair leptin signaling and transport across the blood-brain barrier and thus contribute to the overall progression of AD.¹² If this relationship proves to be relevant in humans, it could lead to the development of novel therapeutic interventions with implications for diagnosis and prevention of AD.

And as the scientists were looking for a mechanism, Venturelli et al¹³ found that people with AD consuming an institutionalized diet had reduced body mass regardless of their energy intake or metabolism. Factors such as hypoalbuminemia, number of medications taken by the patient, and hypercortisolism also contributed to IWL in a manner that was inconsistent between genders. These researchers

TABLE	Functional Assessment Staging (FAST)
Stage	Characteristics of Stage
1	No difficulty either subjectively or objectively
2	Complains of forgetting placement of objects. Subjective work difficulties.
3	Decreased job functioning evident to coworkers. Difficulty in traveling to new locations. Decreased organizational capacity.
4	Decreased ability to perform complex tasks (eg, planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc)
5	Requires assistance in choosing proper clothing to wear for the day, season, or occasion (eg, may wear the same clothing repeatedly, unless supervised)
6	Occasionally or more frequently over the past weeks. For the following:
	(A) Improperly putting on clothes without assistance or cueing
	(B) Unable to bathe properly (not able to choose proper water temperature)
	(C) Inability to handle mechanics of toileting (eg, forgets to flush the toilet, does not wipe properly, or improperly dispose of toilet tissue)
	(D) Urinary incontinence
	(E) Fecal incontinence
7	(A) Ability to speak limited to approximately ≤6 intelligible words in the course of an average day or in the course of an intensive interview
	(B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview
	(C) Ambulatory ability is lost (cannot walk with personal assistance)
	(D) Cannot sit up without assistance (eg, the individual will fall over if there are not lateral rests on the chair)
	(E) Loss of ability to smile
	(F) Loss of ability to hold up head independently
Adapted f	rom Reisberg et al. ^{7,8}

noted their results may not be generalizable to community dwelling persons.

Although IWL continues through the course of AD, even accelerating in advanced AD, in 2017 Hendriks¹⁴ documented that individuals with advanced AD have a diminished sense of hunger and thirst. This symptom is difficult for families to understand as a predictable event in the course of AD. The provision of food and fluids is viewed almost universally as a primary component of care for the sick and dying. Firnhaber and Roberson's¹⁵ review of the literature found nursing home residents, family members, and even healthcare providers often view both failing to initiate and discontinuing attempts to deliver nutrition and hydration by every means possible as poor care, neglect, or abandonment. Furthermore, regulatory and institutional policies, designed primarily to ensure provision of adequate nutrition and hydration for all nursing home residents, may inadvertently impose standard requirements that may not be in the best interest of a resident with advanced AD.¹⁵ Observational studies do not show any benefits of tube feeding in persons advanced AD, leading to the recommendation that they not be initiated.9

Weight loss continues throughout the course of the disease, accelerating in the last year of life.

Researchers note that some reasons for IWL may be addressed with dietary interventions designed to reduce morbidity and improve quality of life. Typical strategies used include ensuring access to food (eg, home-delivered meals, other senior meal programs for community-dwelling elderly, weight-monitoring policies for those living in nursing homes, use of appetite-enhancing medications and nutritional supplements, and treatment of oral health conditions or dysphagia). Additionally, providing assistance for individuals who forget to eat, can no longer prepare foods, or are unable to use regular utensils has been attempted. These interventions may help to prevent weight loss during early stages of AD but may not be effective in advanced AD.^{13,16–19} Our own clinical experiences support this view. Even so, there are continuing efforts, particularly during early-stage AD,²⁰ to see if interventions such as nutritional supplementation, medical foods, pharmacotherapy, or tube feeding can slow the weight loss and lead to different outcomes in advanced AD. Large, randomized controlled trials investigating the effectiveness of these interventions are sparse, as evidenced by the results of a meta-analysis and systematic review, which was unable to establish relationships between specific interventions and mitigation of feeding problems in dementia. It should be noted that

even with broad criteria, such as including all stages of dementia or mild cognitive impairment, few studies were able to be included in this analysis, necessitating further, larger-scale trials to draw further conclusions regarding the effectiveness of specific interventions; however, the authors included a summary of promising interventions, which may guide further research.²¹

Testing and Treating Dysphagia

Up to one-third of people with advanced AD have swallowing difficulty or dysphagia, which may lead to IWL, malnutrition, pneumonia, and death.²² In a typical dysphagia evaluation, the patient is observed at the bedside swallowing different liquids with and without the use of a straw to look for signs of choking, coughing after drinking, drooling, and ability to clearly speak after drinking water. A patient found to have difficulty in the bedside swallow testing would undergo more formal testing to evaluate swallowing function-a VFSE (video fluoroscopic swallowing examination) by speech pathologist and radiologist. The evaluation involves having the patient swallow items mixed with barium and of different thickness and textures ranging from a cookie to water. An x-ray is performed while the patient is swallowing, allowing the radiologist to follow the item as it travels the esophagus to monitor for aspiration. If the patient aspirates, speech pathology typically recommends the diet texture and liquid consistency and consults the registered dietitian nutritionist (RDN) for diet order or prescription. In advanced AD, diet restrictions are not usually practiced. The RDN would include this in the nutrition assessment and plan and would be available to discuss with the patient and family. Our facility is currently using the National Dysphagia Diet²³ but has started the transition to the new International Dysphagia Diet Standardization Initiative framework for individuals with dysphagia of all ages, in all care settings, and for all cultures would be followed.²⁴

If the patient aspirates on the first try with a cracker, the speech pathologist is likely to recommend use of an alternate nutrition route such as a nasogastric (NG), percutaneous endoscopic gastrostomy (PEG), or percutaneous endoscopic jejunostomy tube.

If a patient aspirates any food source, this can lead to infection such as pneumonia.²² In the elderly population, pneumonia can present as altered mental status as seen in the aforementioned case. If a patient is found to have pneumonia thought to be caused by aspiration, a swallow study is typically ordered. A person who fails a swallow test is at risk of an aspiration pneumonia, which is treatable with oral or IV antibiotics. If a person chooses not to pursue antibiotics, signs and symptoms of the infection such as shortness of breath can be treated with palliative care methods. Methods for modifying the texture of foods are described by Batchelor-Murphy et al,²⁵ although a 2017 systematic review of using texture-modified food and fluids in people living with dementia in residential care facilities has not been shown to have an impact on clinical outcomes including aspiration pneumonia.²⁶ These authors suggest that texture-modified food and fluids may lead to poorer intake of food and fluids due to poor acceptance.

Are Feeding Tubes the Answer for IWL or Aspiration in Advanced AD?

Two systematic literature reviews examining the role of tube feedings in advanced AD failed to find evidence supporting long-term survival or improved quality of life.^{4,19} In fact, patients with advanced AD and a feeding tube experienced higher rates of restraint use, increased emergency department visits, and overall lower well-being scores.²⁷ Others, too, have documented increased suffering and discomfort in patients and increased use of restraints.²⁸ Furthermore, their caregivers experienced increased levels of caregiver burden.¹⁸ The ABIM Foundation's "Choosing Wisely Initiative" (www.choosingwisely.org) published a patient report entitled, "Feeding Tubes for People With Alzheimer's Disease; When You Need Them—and When You Do Not." They recommend offering oral assisted feeding instead for people with advanced AD.²⁹

Some PEG tubes, although rarely, are still placed without a clear clinical indication due to disposition concerns and/or social pressures.

Patients' families often are tasked with the difficult decision of whether to pursue artificial means of nutrition and hydration. At one time, an estimated one-third of nursing home patients with dementia underwent the placement of a feeding tube.²⁷ In a 2009 study,⁶ only 1 in 3 (32.5%) of healthcare proxies reported that a physician had discussed the trajectory of dementia and the likely complications, including feeding problems and IWL that their loved one would experience. We did not find an estimate for the rate of tube placements any more recent than 2003. Although, Teno et al³⁰ in 2012 found that only 5.4% of around 36 000 nursing home residents with advanced AD had a feeding tube placed and reported providing only a minimal difference in survival benefit in comparison to those without. In the absence of other literature reports, we queried our surgical colleagues about the rate of tube placements in our facility. The practice in the overwhelming majority of cases is not to place a PEG tube. However, some PEG tubes, although rarely, are still placed without a clear clinical indication due to disposition concerns and/or social pressures. The practice may vary across regions and facilities and may differ with the presence of a wellorganized and integrated palliative care program.

The difficulty but importance of addressing these decisions, even for healthcare providers not directly involved in decisions, should not be overlooked. One study of nursing staff providing end-of-life care in a nursing home found they too struggled with knowing how best to address and support feeding issues and decisions. They reported using a variety of creative efforts to maintain oral intake and communicating issues to family members and medical providers when they arose or changed. Their actions were impacted by their personal beliefs and experiences, relationships they had with the individual residents and their family members, organizational culture, and the nature of these feeding issues near the end of life.¹⁵ We will discuss alternatives to feeding tubes in advanced AD later in this article.

Putting the Advance in Advance Care Planning

There are many different resources to help individuals and their families make informed choices about end-of-life care. The National Institutes of Aging³¹ provides a clear discussion of advance care planning (ACP) and health care directives, as well as legal and financial planning for people with AD at their website (https://www.nia.nih.gov/health/ legal-and-financial-planning-people-alzheimers). Unfortunately, conversations regarding ACP are often initiated when the patient is hospitalized, actively dying, or refusing oral intake. It is imperative that healthcare teams discuss with patients and their families the expected disease trajectories early after diagnosis, including the goals expected of all care choices available. In the event that the discussions were not accomplished in the early stages of AD, the discussion should still be held with the patient's proxy. In a study of nursing home patients with feeding difficulty, IWL was found to be an independent predictor of death.³² If this observation is generalizable, it demands that the goals of care must be discussed.

In order to easily facilitate ACP, a physician orders for life-sustaining treatment (or a POLST) form³³ can be used to record a patient's treatment wishes, taking into consideration values and beliefs, diagnosis and prognosis, and treatment options, including the benefits and burdens of those treatment options. In our state, the medical orders for scope of treatment (or a MOST) form³⁴ is recognized (https://info.ncdhhs.gov/dhsr/EMS/pdf/ncmostform.pdf). It is easily completed in one visit, requiring only the provider and patient or proxy signature. It covers topics such as code status, medical interventions, and desire for antibiotics, IV fluids, and artificial nutrition. Most experts suggest counseling the patient and family that there are few studies to support the belief that tube feeding is beneficial.³⁵ Regardless of the method of feeding, the risk of aspiration and aspiration pneumonia is still present. The healthcare

team should discuss and document with families what treatment they may choose (eg, antibiotics or palliative care) for shortness of breath or other symptoms of infection. If a patient has failed a swallow study, they will likely develop a pneumonia at some point in the future.

Healthcare professionals, too, should prepare themselves to provide the best possible care to the patients and their caregivers. The Academy of Nutrition and Dietetics has position papers describing the role of the RDN and the interprofessional team in assisting patients and their caregivers in making and honoring informed choices related to feeding in advanced AD.^{36,37} There are also other guides, for example, a 12-step program to developing dementia-capable healthcare.³⁸ Regarding tube placements, Chung³⁹ suggested that the interventional radiologist who places the tube is obligated to ensure a full discussion of the disease trajectory, risks, benefits, and indications for the procedure that has occurred.

There are investigators working to improve ACP in hopes of improving healthcare proxies' understanding of end-of-life care. Videos can show the realities of tube feedings as well as comfort feedings. To date, ACP interventions have had mixed responses, and more work is needed.^{40,41}

It would be good for healthcare providers to read the articles and books caregivers publish about their journey with their mother, father, spouse, or loved one. Healthcare professionals need to understand what dementia does to the person who lives with the condition as well as their caregivers. A long-standing favorite of many providers is *The 36-Hour Day*, now in its sixth edition.⁴² We also recommend Nicci Gerrard's *The Last Ocean*. A Journey *Through Memory and Forgetting*.⁴³

What Are the Alternatives to Feeding Tubes?

The AGS^{2,44} position paper states careful hand feeding should be offered because hand feeding has been shown to be at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status, and comfort. Hand feeding requires skills including (1) managing dysphagia and risk for aspiration, (2) interpreting and managing feeding behaviors, and (3) promoting independence in eating.⁴⁵ There are few reports directly comparing outcomes from tube and assisted methods; however, a study in Taiwan⁴⁶ comparing assisted hand feeding versus NG feeding did show there was not an increased rate of hospitalization among patients who received assisted hand feeding. In fact, they found a trend of increased risk of pneumonia in patients receiving NG feeding. Batchelor-Murphy et al²⁵ provide a detailed description of hand feeding techniques. Earlier,⁴⁵ they found that direct hand, over hand, and under hand all took about the same time but that under hand and direct hand better managed feeding behaviors such as turning the head away and clamping the mouth shut. Some individuals with AD may have advance orders that stipulate

feedings stop in advance dementia. The ethics subcommittee of the Society for Post-Acute and Long-term Care Medicine provides arguments for and against Stopping Eating and Drinking by Advance Directives in individuals with advanced AD.⁴⁷ They suggest those orders not be implemented as long as the individual is willingly accepting food and drink-that comfort feeding be provided. The AGS further recommends that efforts to enhance oral feeding by altering the environment and creating individual-centered approaches to feeding should be part of usual care for older adults with advanced AD. Some physicians recommend the adoption of specific orders, such as comfort feeding-only orders, which would guide caregivers to offer food and liquid as long as it is not distressing, enjoyable, and comfortable. The "comfort" in comfort feeds has a 2-fold meaning, emphasizing that eating does not become distressing to the individual as well as the goal of feeding. Comfort feeding-only orders allow the individual the social closeness by allowing careful handing feeding from a caregiver but discontinuing the feed at signs of distress. The patient should not be force fed, and the least invasive method should be used while continuing to interact with the patient.^{48–51} The authors of a Cochrane Review⁵⁰ conducted to identify what environmental and behavioral modifications improved food and fluid intake in people with dementia concluded that there were only a few and only small studies, with design flaws including failure to identify the stage of AD. This did not allow them to identify effective interventions. Published after the Cochrane review was a study of a nurse-guided hand exercise program in patient with AD that demonstrated improved feeding behavior end points.⁵¹

We acknowledge that not all agree that tube feedings are wasteful or unnecessary procedures. Lynch⁵² argues that guidelines promoting careful hand feeding are based on studies that are flawed and lead to underestimating the benefit and exaggerating the burdens of tube feeding. Also, a recent Japanese study cited a significant survival increase of 23 months in patients with advanced AD who received feeds through a PEG or NG tube compared with 2 months in patients of a similar stage without tube feeds.⁵³ One head-to-head study found the PEG tube feeding gave greater survival than the NG tube feeding.⁵⁴ These reports give little information, however, about factors such as patient comfort and dignity, quality of life, patient functionality, hospitalizations, and emergency department visits. We agree with the number of major medical societies and organizations, including the AGS, that tubes should be placed in patients with advanced AD only rarely, if at all, and that these studies do not overshadow the overwhelming evidence and recommendations set forth by them. Because of the limited amount and the quality of the evidence, we are left to recommend an interprofessional approach be used in feeding patients with advanced AD.37 We suggest including caregivers and a variety of professionals including

RDNs, speech therapists, occupational therapists, nurses, and physicians for individuals receiving care at home or in a residential facility.

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CASE REVISITED

Mrs D. underwent a formal video swallow evaluation and failed. Speech therapy recommended an alternative form of nutrition such as an NG tube or PEG tube. The physician noted temporal wasting, a component of the comprehensive nutrition assessment, which indicated malnutrition. Unfortunately, ACP had not occurred. Her family was presented with all options, including short-term NG, PEG versus percutaneous endoscopic jejunostomy, or hospice with comfort feeds. Mrs D.'s family asked questions related to how comfort care would proceed if she were discharged home with hospice. The physician counseled the patient's family that Mrs D. could eat and drink for comfort, knowing that the risk for aspiration pneumonia remained. The family was given patient education materials and the opportunity to talk with the hospital RDN about an appropriate eating plan. Her shortness of breath, pain, and anxiety would be treated to promote her comfort and dignity. Her fever would also be treated, if one developed it as a result of an infection. The physician reviewed the lack evidence with the family regarding PEG tube placement in people with advanced AD, noting that neither the quality of life nor longevity has been shown to improve with such an intervention. All care would be delivered at home, unless her symptoms were unable to be adequately managed in that setting, at which point she could be transferred to inpatient hospice. After much discussion with the family, the healthcare proxy completed a MOST form and decided to initiate hospice care with comfort feeds.

SUMMARY

We summarized current literature addressing feeding the individual with advanced AD. Unfortunately, there continues to be a void in the literature describing the prevalence of tube feeding and effective strategies when caring for these individuals. We feel it is imperative for physicians and other healthcare providers working in the field of dementia to be prepared to counsel patients and families on the expected disease trajectory and anticipated stages of health decline. Informed and well-thought-out decisions can be made regarding goals of care and avoidance of unnecessary interventions in advanced AD. We agree with the evidence cited previously that feeding tubes likely do not improve the quality of life or the survival of patients with advanced AD.

Feeding the Patient With Advanced AD Post–COVID-19 Outbreak

Since the acceptance of this article, the environment surrounding ACP and care of the elderly has been greatly impacted by COVID-19. The AMDA⁵⁵ provided recommendations for "Caring for Post-Acute and Long-term Care Residents With Dementia During the COVID-19 Outbreak." The Alzheimer's Association's document, "Emergency Preparedness: Caring for Persons Living With Dementia in a Long-term or Community-Based Care Setting" provides additional suggestions that also may be applicable to those being cared for at home.⁵⁶ Nursing homes and assisted-living facilities have been on lockdown with no one other than staff allowed to enter. Prior to COVID-19, residents in one of our local memory units, who did not require significant assistance with eating, ate family style. At the time of this writing, the practice continues as staff recognize the importance of the social and emotional benefits of eating along with the goal of promoting independence. They are bringing fewer residents to the table at any given time. In some facilities, all group dining has been suspended completely and residents eat in their rooms. There are obstacles to providing care such as comfort feeding with family and other personal caregivers restricted from assisting. Family members, too, feel loss of control to ensure their loved one is eating and drinking. Additionally, masks worn by all staff of facilities make it more difficult to communicate with and treat individuals with advanced AD. And although family members might be able to FaceTime or have window visits, it is difficult for residents who are nonverbal. We are aware that major disruptions have occurred in the lives of those providing care to individuals at home as well.

We would again stress the importance of ACP as well as open conversation with patients and their family members regarding end-of-life care with any disease state or situation.

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