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Artificial nutrition, advance directives and end of life in nursing homes

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14 Artificial Nutrition, Advance Directives, and End-of-Life in Nursing Homes

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14.1 INTRODUCTION

More than 30% of people living in nursing homes in the United States die there or within a short time after transfer to an acute care facility, highlighting the need for an increased focus on delivery of palliative care services (Center for Disease Control and Prevention 2002). A significant part of this care requires consideration of the resident's preferences for life-sustaining treatment. One manner in which these preferences are communicated is through advance directives (ADs) executed by the residents. Although a variety of treatments may be addressed, artificial nutrition (AN) has attracted significant attention. In the recent case of Terri Schiavo, a young American nursing home resident in a persistent vegetative state receiving AN, commentary spread across the world, including a papal address. In light of society's continuing struggle with this life-sustaining treatment, this chapter addresses nursing home care, ADs, and AN for those at the end-of-life.

14.2 NURSING HOMES

14.2.1 Personnel to Meet the Demands

As individuals live longer with serious illness, many require skilled care that can be found in long-term care facilities also known as nursing homes or care homes (The Care Commission 2009). Increasingly, these facilities are becoming the place for many to die with an expectation that this number will rise significantly in coming years (Center for Disease Control and Prevention 2002). With these numbers comes an increased demand for staff to care for more residents. The Center for Medicare and Medicaid Services in the United States recently provided minimum guidelines on appropriate staffing for nursing homes, concluding that 90% of the homes were already deficient in meeting these standards (Abt Associates 2001). Poorer staffing translates into more residents per staff member, causing the potential for significant workplace stress and higher rates of staff turnover. This lack of stability further erodes the quality of care in general and palliative care in particular.

In some instances residents who are capable of eating may receive AN due to poor staffing. These residents require hand feeding and in the absence of family or volunteers to assist, may not receive adequate nutrition because of the time it takes to feed them. Although some may feel that AN is more expedient and will provide all the necessary nutrients, residents are deprived of the innate social nature of mealtime.

14.2.2 Palliative Care Services

More residents not only demand higher staffing ratios, but staff capable of providing overall as well as palliative care. Recent research documents the lack of appropriate palliative care services in nursing homes such as the inconsistency of care with patient preferences (Teno et al. 2004) and the lack of awareness that palliative care should be delivered to specific residents (The Care Commission 2009). Statistics are available on multiple aspects of palliative care, however for the purposes of this chapter, the focus will remain on life-sustaining treatments, specifically AN.

14.2.3 Palliative Care Education

The lack of palliative care in nursing homes may be attributed to inadequate attention by staff development departments within homes (International Council of Nurses 2002), as well as the absence of proper education within basic nursing curricula (McDonnell et al. 2009; The Care Commission 2009). Further, with higher staff turnover rates, the effectiveness of educational programs is limited, requiring educators to continually re-educate new groups of employees. Consideration of these educational needs is important to fostering appropriate educational programs in nursing homes (Table 14.1).

Although there is a significant body of literature on the palliative care educational needs of nursing home staff, there are few studies on the effect of systematic organized education in this area. In one study, the presence of a palliative care program in a group of nursing homes positively impacted the knowledge level and attitudes of staff (Stillman et al. 2005). It is clear that education is a positive force in improving palliative care, however historical events in the regulation of nursing homes may add to the difficulty in realizing appropriate palliative care.

14.2.4 Regulations

Nursing home regulations exist for the protection and welfare of residents. In Ireland, both publicly and privately owned nursing homes are subject to regulations (Health Information and Quality Authority 2008), recognizing the need for palliative care knowledge and basic skills (An Bord Altranais 2009). Scotland's Commission for the Regulation of Care recently reported mixed results on the provision of palliative care in care homes (The Care Commission 2009).

TABLE 14.1
Palliative Care Education in Nursing Homes

- Examine the underlying culture of the institution
  - Survey staff and administrators
  - Capture beliefs and values
  - Include a values clarification exercise
- Develop a plan for palliative care education
  - Use multiple strategies
  - Provide the basics first
  - Include plans for remediation
  - Provide support for staff to attend
  - Plan ahead for continuing education
- Include all parts of the organization in educational sessions
  - Administration, clinical, and support staff
  - "Buy in" is essential for success
- Develop an advance care planning protocol
  - Identify key staff who will approach residents and families
  - Identify a timeline for completion of the process from admission
  - Reinforce need for consistency of message to residents and families
- Develop a standard advance directive
  - Begin with a standardized document to avoid omissions
  - Allow for additions by residents and families
- Reinforce necessary documentation
  - Document advance care planning process
  - Document resident's preferences on an advance directive
  - Standardize the location for all documentation
- Reinforce the ongoing process
  - Preferences may change so continuous communication is key
  - Support of resident and family

Note: This table presents key steps in the process of initiating a palliative care education program in a nursing home. The process includes the mechanics as well as the need to incorporate psychosocial and cultural aspects of program development. In addition, ongoing support, evaluation, and readjustment of the program is necessary to maintain a healthy and viable palliative care education program.

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Abuse and neglect in the mid-twentieth century U.S. nursing homes necessitated the institution of regulations to insure adequate nutrition and hydration. These regulations utilized resident weight as an indicator of nutritional adequacy unless further documentation identified a reason that this goal could not be achieved (Omnibus Budget Reconciliation Act 1987). A resident's refusal to eat or drink was not considered in applying this regulation, thereby increasing the possibility that AN would be instituted to maintain compliance. In addition to OBRA 1987, U.S. nursing homes receiving funds from Medicare (a federally funded program) or Medicaid (a state-funded program) must collect specific nutritionally related data on each resident as part of the Minimum Data Set (MDS) (Table 14.2).

Although weight may be one indicator of poor nutrition, it is one of many that must be assessed in the palliative care population. Difficulty in standardization of procedures and equipment lead to inaccuracies in reporting of actual weights. Disease processes and aging also affect the weight in terms of measuring lean body mass, fat, and extracellular fluid changes (Monturo and Strumpf 2007). Fear of litigation and/or loss of institutional accreditation may increase the use of AN without considering the residents' preferences and quality of life, or that weight loss is a common indicator of impending death (Center for Gerontology and Health Care Research Brown Medical School 2004).

TABLE 14.2
Minimum Data Set (MDS) Nutritional Parameters

- Oral problems
- Height and weight
- Weight change
- Altered taste
- Hunger
- Uneaten meals
- Food intake
- Use of nutrition support
- Use of mechanically altered food
- Use of therapeutic diets

Note: The MDS is a data repository for information collected on all residents in nursing homes receiving state or federal funding in the United States. This data is used to assess residents, but is also extensively used for research purposes as it is easily accessible through internet sites.

14.2.5 COGNITIVE IMPAIRMENT

Dementia results in many neurodegenerative impairments, including eating difficulties in its final stages. Recent statistics show that 70% of those with dementia are expected to receive end-of-life care in nursing homes (Mitchell et al. 2005). Although the use of AN is not exclusive to those residents with dementia, reports show that it is highest in those with significant cognitive impairments (Mitchell et al. 2003). In addition to dementia, those with other forms of cognitive impairment, such as a individuals in a persistent vegetative state, a minimally conscious state, or a coma, are unable to eat normally and therefore AN may be provided.

14.3 ADVANCE DIRECTIVES

ADs are considered the written result of advance care planning and must not exist in isolation as simple documents (Figure 14.1, Table 14.3). ADs may be standardized to include certain language, such as those in individual U.S. states, or may be available to the general public. Routinely, ADs contain directions to allow or refuse specific medical treatments. In this manner they may also be called 'living wills.' Another form of AD is the power-of-attorney for healthcare decisions. This AD identifies an individual who will make decisions for the resident should they no longer be able to communicate their own wishes. These two types of ADs may also be combined into one document, such as Five Wishes offered by the organization *Aging with Dignity*. In some Asian cultures, ADs are viewed as a liberal model for decision-making and one that is not central to normal familiar relationships (Chan 2004). Although advance care planning and ADs exist in numerous forms in many countries, the United States continues to experience much difficulty with this issue, specifically as it relates to AN. For that reason, much of this section is dedicated to information derived from the United States.

14.3.1 HISTORICAL EVOLUTION

In the latter part of the twentieth century, the literature focused on advance care planning and specifically ADs in the United States, originating from legal mandates and the right to die movement, unlike the previous focus on "do not resuscitate" orders and a less autonomous environment (Figure 14.2). The first right to die case was that of Karen Ann Quinlan, a young nursing home resident in a persistent vegetative state supported on a respirator. Although the case involved

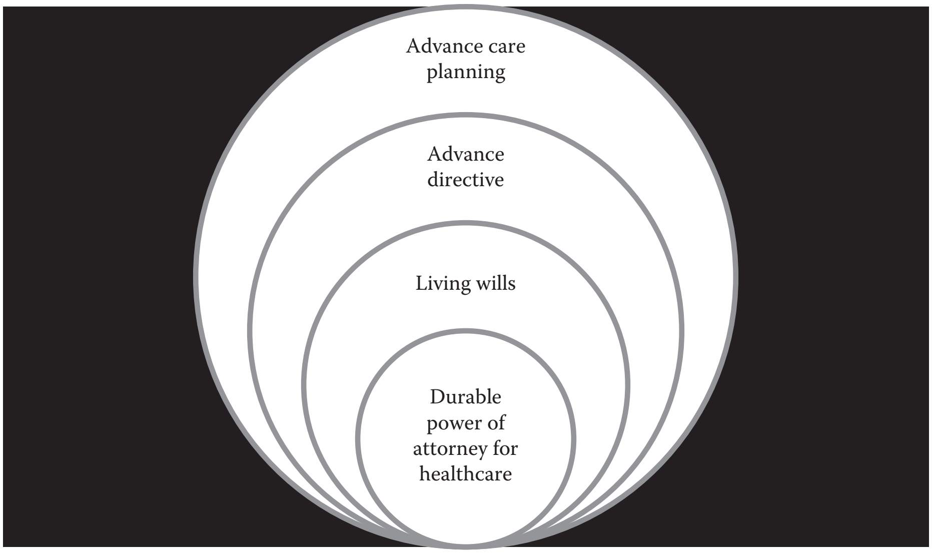

FIGURE 14.1 Advance directives. Advance care planning is the overarching and inclusive approach to advance directive development.

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discontinuation of a respirator, removal of AN was also an option, but one which was not acceptable to her family at that time. Ms. Quinlan died 9 years later of pneumonia while still receiving AN.

Numerous cases arose after Ms. Quinlan, focused on withdrawal of treatment, sometimes including AN. At this time, some believed there was a difference between withdrawal of AN and withdrawal of antibiotics, respirators, or other medical treatments. Seven years after the Quinlan decision, medical and ethical experts found no difference between AN and other life-sustaining treatments (The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983). Despite this ruling, societal struggles concerning this life-sustaining treatment continued in the United States. As a result of a newborn case, federal regulations known as the "Baby Doe Directives" were imposed preventing withdrawal or withholding of nutrition and fluids from a newborn based solely on a disability.

In 1990, as a result of the Nancy Cruzan case, the U.S. Supreme Court provided support for individual states' rights in upholding a requirement to provide clear and convincing evidence of an

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TABLE 14.3
Key Features of an Advance Directive

- It is a document but should be supported by a plan of care
- An AD provides directions for care when an individual is unable to communicate
- ADs may be modified over time
- Actual templates or documents vary with country/state
- ADs may be developed using two basic forms: a living will and a durable power of attorney for healthcare
- ADs are considered legally valid in some areas
- ADs may also be seen as an "individual's voice"
- Enforceability of advance directives also varies with locale
- There is no expiration date on an advance directive
- ADs require preparation prior to execution of the document

Note: Advance directives vary according to locale, however they contain basic information necessary to communicate the preferences of residents no longer able to describe their wishes.

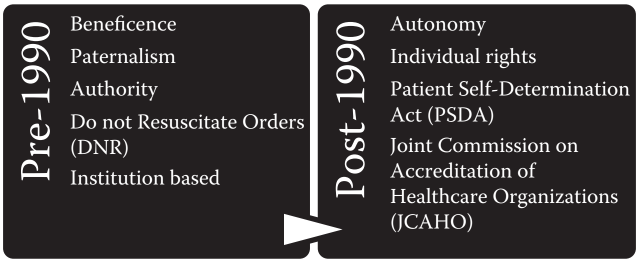

FIGURE 14.2 Historical evolution of advance directives. As a result of the right to die movement, a focus emerged on autonomy and individual rights after years of paternalism and authority-based decision-making. More formal advance directives arose from this evolution post-1990.

AU: Should this read In re Cruzan v. Director et al.?

individual's wishes concerning treatment (In re Cruzan v. Director 1990). Similar to Ms. Quinlan, Ms. Cruzan was a young woman in a persistent vegetative state, however in this case the issue was withdrawal of AN. Eventually, Ms. Cruzan's AN was discontinued at the request of her family after they provided additional evidence of her wishes. At the same time, a U.S. act known as the Patient Self Determination Act was put into place concerning ADs. Upon admission to a nursing home, staff were required to ask residents if they possessed an AD and to provide information regarding the right to complete an AD (Omnibus Budget Reconciliation Act 1990).

Despite court rulings, ethics panel results, and federal acts, other cases continued to appear, evoking strong emotions. The case of Ms. Terri Schiavo, the most recent involving AN to reach national attention, continued the debate, although in this instance the issue was which surrogate had power over this decision—a spouse or a parent. In all these cases, individuals did not have previous documented treatment wishes, ADs, and therefore discussions led to surrogate decision-making, court-appointed guardians, and/or a best interest standards.

14.3.2 Usefulness of Advance Directives

The presence and successful use of ADs is variable (Center for Gerontology and Health Care Research Brown Medical School 2004; Monturo and Strumpf 2007; Teno et al. 1997). Some report that given the number of years that ADs have been available, there continues to be poor utilization and that this venture has essentially failed (Fagerlin and Schneider 2004). Others would argue that the combination of palliative care education, planning, and AD can work; however more focus must be placed on the plan and education than merely on a document (Monturo and Strumpf 2007; Stillman et al. 2005).

Limited data exists on the incidence or frequency with which preferences for AN appear in ADs. One study reported a high rate of AN preferences (94%) in ADs, although this was likely attributed to the existence of a previously conducted palliative care study in these nursing homes (Monturo and Strumpf 2007).

14.4 ARTIFICIAL NUTRITION

AN is known by many different names including enteral nutrition, parenteral nutrition, and tube feedings. Hydration is frequently included when discussing AN; however these two treatments are distinct. Although both are delivered as a fluid, hydration is simply intravenous fluids with minimal sodium or dextrose, depending on the formulation, whereas enteral (tube feeding) and parenteral nutrition contain micro- and macronutrients necessary to sustain life. AN originated as a means to nourish those unable to ingest food and fluids due to temporary or chronic illness. Although the success of AN is widespread in the literature, its overuse in palliative care and in severe cognitive impairments such as advanced progressive dementia or persistent vegetative states may create ethical dilemmas for residents, families, and healthcare providers (Monturo 2009).

14.4.1 Enteral Nutrition History

Enteral nutrition or "tube feeding" is more common in nursing homes and thus will be the focus of this discussion. This treatment dates to ancient times and throughout the centuries has taken on a variety of different forms (Randall 1990). Technological advances in surgical procedures led to the development of the percutaneous endoscopic gastrostomy (PEG) tube. Placement of this tube afforded patients a decreased risk of complications. The three-fold increase in placement of gastrostomy tubes in older adults over the past 20 years (DeFrances, Cullen, and Kozak 2007) may be due in part to the relative ease of PEG tube placement.

14.4.2 Enteral Nutrition Use

The use of AN in U.S. nursing homes is well documented and, as noted earlier, appears to be higher in those with advanced cognitive impairment (Mitchell et al. 2003); therefore the majority of literature on enteral nutrition in nursing homes focuses on those with dementia. There is little evidence that AN is prescribed for those with dementia in other parts of the world. The rate of AN in the United States may also vary by individual nursing home, state, community (rural vs. urban), and by nursing home culture (Gessert, Elliott, and Peden-McAlpine 2006; Mitchell et al. 2003; Palan Lopez et al. 2010; Teno et al. 2002). Despite the significant number of U.S. nursing home residents receiving AN, there is no evidence to support that this treatment is beneficial to those with dementia (Candy, Sampson, and Jones 2009). Unlike orally ingested food, delivery of enteral nutrition is not free from complications. These complications may be mechanical and therefore directly related to the tube, or physiological (Figure 14.3). As a result, efforts should be made to avoid AN in end-of-life care and instead consider viable alternatives.

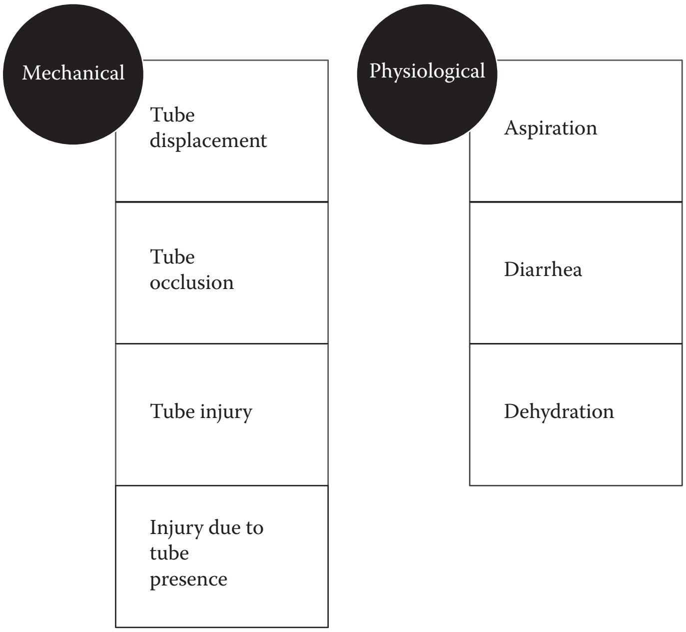

FIGURE 14.3 Enteral nutrition complications. Complications with enteral nutrition are divided into two categories: mechanical and physiological. Mechanical complications are associated with the actual device, the tube, whereas physiological complications encompass the body's reaction to enteral nutrition.

TABLE 14.4
Guidelines for Alternatives to Artificial Nutrition

Intact Swallowing Function	Swallowing Deficit
Adjust food consistency for ease of ingestion	Determine limitations for oral intake[a]
Determine likes/dislikes and tailor menu	Provide frequent mouth care
Encourage family/friends to bring appropriate foods	Provide frequent skin care
Arrange food attractively on small plates	Instill lubricant eye drops for dry eyes
Provide small frequent meals	Encourage family to assist with physical care
Medicate as necessary to control pain and/or nausea	Medicate as necessary to control pain and/or nausea
Be aware of resident's wishes	Encourage other nurturing activities in place of food (singing, massage, reading, music, photographs)
Goal is not nutritional repletion, but comfort or pleasure	Goal is comfort and helping to replace the "food connection" between resident and family

Note: For those individuals who choose not to accept artificial nutrition at the end-of-life, there are alternatives. This table offers suggestions for those with intact swallowing function as well as those with a swallowing deficit.

[a] For those with a swallowing deficit, families must consult with healthcare providers concerning the limitations for oral intake since the risk of aspiration must be discussed and a decision made to either accept or reject the idea of providing tastes or sips of food/fluids at the request of the resident at the end-of-life.

14.5 PRACTICAL GUIDELINES FOR ALTERNATIVES TO ARTIFICIAL NUTRITION

Without the potential for alternatives to AN, practitioners would be forced into a black and white decision to initiate, maintain, withhold, or withdraw AN in end-of-life situations. To avoid this dilemma and to assist the resident and family through the grieving process, guidelines have been developed to address both those residents with an intact gag/swallowing reflex and those with some level of swallowing deficit (Table 14.4).

These guidelines contain ways to provide oral nutrition or fluids for those with intact swallowing function, but more importantly provide other means to comfort residents without the need for food. Historically, eating and feeding are viewed as nurturing or caring functions. For many, food is an integral part of secular as well as religious holidays. Food is also central to gatherings for mourning or grieving a loss, assuring that all will be fed and nurtured.

In this respect practitioners must develop different methods to reconnect or maintain the connection between residents and families at end-of-life. These methods must be based on knowledge of the family and resident, information that may be discovered during the advance care planning process (Monturo 2010).

14.6 KEY FEATURES OF NURSING HOMES

Regardless of country, nursing homes provide care for those unable to care for themselves.

Some may provide only custodial care, while others may have subacute and rehabilitation units.

Nursing homes are not limited to the care of older adults. Younger adults with life-limiting or severely debilitating and chronic conditions are also treated.

Nursing homes are regulated so as to provide safe and effective care to all residents. These regulations differ based on country/state.

Some nursing homes may be modeled on a hospital type ward with individual rooms off a corridor and no access to a kitchen.

Other nursing homes offer a more home-like and inviting milieu such as the new Green Houses featuring central kitchens and great rooms with resident rooms off this space.

The cost of nursing home care is variable across countries and may be the responsibility of the resident, the family, the insurance company, the health service, the state and federal governments, or a combination of these entities.

ETHICAL ISSUES

The use of AN in end-of-life care is not supported by research and it is not beneficial to those with dementia, according to recent results from the Cochrane Collaboration (Candy et al. 2009). Despite this, some nursing home residents with dementia or other terminal illnesses continue to receive AN. Perhaps the recent notoriety of the Terri Schiavo case and John Paul II's papal address on AN highlight an ethical dilemma: is artificial nutrition a medical treatment or basic life support? Notwithstanding the ethics panel's findings from more than 20 years ago, individuals continue to struggle with the notion of "not feeding" or starving a loved one. Starvation is a highly emotive word and one filled with individual images of pain and suffering. Similarly the emotions connected with the meaning of food are based on individual values and beliefs and comprise one's life story (Monturo 2009; Monturo 2010). Examination of the meaning of food and individual nursing home cultures may provide insight as to the necessary changes and ongoing intensive palliative care education required for compassionate and clinically appropriate end-of-life care for nursing home residents.

SUMMARY POINTS

- Nursing homes will increasingly provide a substantial portion of end-of-life care.
- The lack of appropriate palliative care education in nursing homes is well documented.
- Advance directives are one part of the advance care planning process.
- The right to die movement began the discussions of withdrawal and withholding of life-sustaining treatments such as artificial nutrition.
- Artificial nutrition is a viable option for treatment of temporary illnesses.
- Artificial nutrition is not beneficial in those with advanced dementia.
- Nursing home culture and geographic community may affect the rate of artificial nutrition delivered in that particular home.
- An ethical dilemma exists for some who believe that artificial nutrition is synonymous with food and that withdrawal or withholding this treatment is tantamount to starvation.
- Examination of the meaning of food for residents and families is necessary to plan appropriate end-of-life care.

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LIST OF ABBREVIATIONS

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AD	Advance directive
AN	Artificial nutrition
MDS	Minimum Data Set
OBRA	Omnibus Budget Reconciliation Act
PEG	Percutaneous endoscopic gastrostomy

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