

Withholding and Withdrawing Life-Sustaining Treatment in Advanced Dementia: How and When to Make These Difficult Decisions

Dylan Harris, MBBCh(Hons), MRCP, DipPallMed, Specialist Registrar in Palliative Medicine, Princess of Wales Hospital, Bridgend, UK.

Dementia is a progressive incurable illness. In the advanced stages of the disease, decisions need to be made whether to withhold or withdraw life-sustaining treatment. This article reviews the principles of deciding a patient's best interests when he or she lacks mental capacity, the role of advance statements, and principles for the practising physician to consider in common withholding/withdrawing treatment scenarios that arise in clinical practice, such as artificial feeding, cardiopulmonary resuscitation, and antibiotics for pneumonia.

Key words: dementia, palliative care, withholding and withdrawing treatment, artificial feeding, resuscitation, antibiotics

Introduction

Worldwide, the number of people diagnosed with, and dying from, dementia and its associated complications is rapidly increasing.^{1,2} In advanced stages, the disease is characterized by the inability to recognize family members, a high dependency with activities of daily living, the inability to communicate, and repeated infections and other complications such as pressure sores.^{3,4}

Palliative care has an important role in the care of patients with dementia and encompasses the active holistic care of patients with advanced progressive illness to achieve the best quality of life for them and their families (Figure 1).^{2,5}

It is important for health care profes-

sionals to recognize that dementia is a terminal illness; specific prognostication, however, is difficult.^{2,6-9} The “surprise question,” that is, “Would you be surprised if this patient were to die in the next 6–12 months?” has been suggested as a useful trigger to identify patients who are approaching the end of life.¹⁰ There are also dementia-specific prognostic scoring tools¹⁰ and other scales, such as the Mini-Suffering State Examination (MSSE), which can also provide prognostic information.¹¹

Deciding whether to withhold or withdraw life-sustaining treatment becomes increasingly relevant as the disease progresses and prognosis shortens—in particular, where benefits of

intervention, if any, are uncertain; where potential harm or burden is likely; and where quality of life is poor. Whether to provide artificial feeding, antibiotics in the management of pneumonia, and cardiopulmonary resuscitation are common such dilemmas.^{1,4,6,7,12,13}

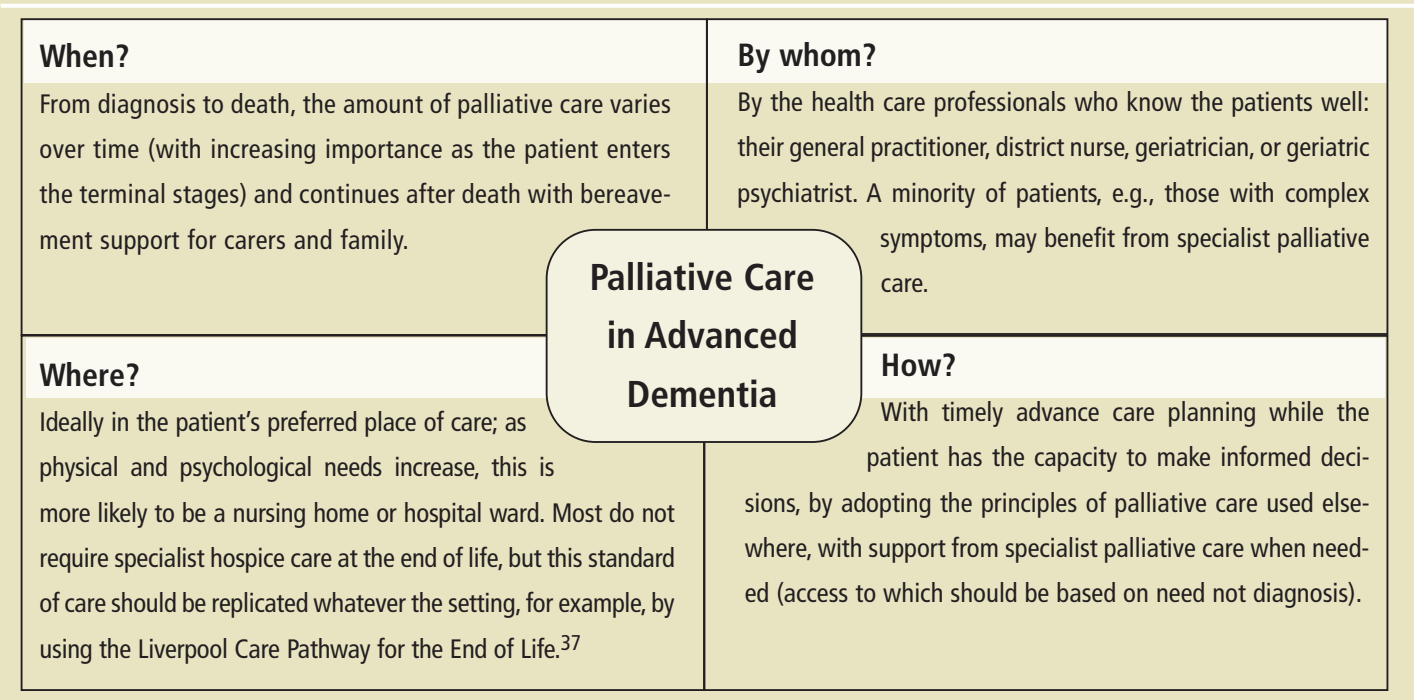
Withdrawing or Withholding Treatment: Principles of Decision Making

Decision making for patients with advanced dementia can become challenging once they have lost mental capacity and are not able to participate in discussions about goals and aims of care.¹⁴ To have mental capacity, patients should be able to understand information pertaining to the decision about to be made; be able to retain that information; use that information to consider the pros and cons and make a balanced decision; and communicate that decision.¹⁵ Mental capacity is specific to each decision; therefore, patients may have capacity to make some decisions but not other (more complex) ones. Patients who do not have the mental capacity to make decisions may still be involved in the process.

When patients lack the capacity to make a decision, doctors should ascertain whether they have previously expressed their views and whether an advanced statement has been made.¹⁶ However, physicians should not be compelled to provide treatment they consider to be futile and medically ineffective.¹⁶⁻¹⁸ The opinion of family and carers is also important, particularly if patients have legally given them power in decision making in relation to medical treatment.¹⁹ If a consensus agreement cannot be reached, it is advisable to seek an independent medical review or legal opinion.¹⁶

Key considerations in making “best-interest” decisions are the expected clinical effect (benefit) of an intended treatment; any potential adverse harm or burdens from the intended treatment; and the patients’ wishes (if previously known or documented). These considerations broadly relate to the ethical principles of beneficence (doing good),

Figure 1: Palliative Care in Dementia—A Model of Care



nonmaleficence (avoiding harm), and respect for patient autonomy. The principle of “justice” is also relevant—for example, the balance of costs and resources used for one dementia patient against costs and resources available to others. Examples of situations where treatment may be initiated / continued or withheld / withdrawn are listed in Table 1.

There is no ethical or legal distinction between not starting a treatment and withdrawing a treatment when it is felt to not be in a patient's best interests.^{16,18,20} Withholding or withdrawing life-sustaining treatment is a decision that allows the disease to progress on its natural course, in contrast to euthanasia, where the intent is to seek death and end life.¹²

Advance Directives

Advance care planning is fundamental in the management of advanced dementia.^{2,9} An advance directive (also called a *living will*) is a signed statement of medical preferences. Patients may also appoint a power of attorney to make future decisions for them. This would be a trusted individual who would make decisions based on knowledge of the

patient's wishes.²¹ The appointment of a power of attorney does not guarantee that the wishes of the patient will be carried out; it merely means that he or she will be represented.²¹

Advance care planning offers the patient the opportunity to make decisions about end-of-life care and maintain some control. The issue needs to be approached sensitively *early* in the disease while the patient is still mentally competent to make such decisions.

Withdrawing and Withholding Treatment: Antibiotics, Resuscitation, and Feeding Role of Antibiotics in the Treatment of Pneumonia

Patients with advanced dementia are particularly vulnerable to infection.¹³ The mortality from pneumonia is over four times higher among individuals with dementia than among similarly matched cognitively intact patients.^{3,22–24} Pneumonia has been described as the “demented patient's best friend” as it is characterized by an “acute, short, not often painful illness.”^{25,26}

Antibiotics can be given with curative intent (where achieving cure of the

pneumonia is the primary goal) or with palliative intent (to help maintain quality of life and for symptom control, for example, by reducing purulent chest secretions).^{17,27} However, treatment also carries potential burdens and complications such as the development of antibiotic-associated diarrhea.

Research suggests that death from pneumonia is associated with discomfort,²⁶ and pneumonia may therefore not be the friend it was traditionally considered to be. However, antibiotics do not appear to significantly reduce the discomfort (or mortality) in this patient group,^{8,26} and for many patients, fever management with regular acetaminophen may be sufficient.^{27,28}

Medical factors that may inform best-interest decisions when considering antibiotics include the overall physical health status of the patient, the patient's estimated life expectancy, the patient's ability to communicate (actively and passively), and the severity of the dementia.^{7,17,29} In addition, a number of factors appear to predict mortality from pneumonia in persons with dementia: increased respiratory rate, decreased alertness, reduced fluid intake, and eat-

ing dependency have been found to correlate with death within 1 week.²³

Patients with dementia are particularly vulnerable to death from bronchopneumonia, and antibiotics may not change this outcome in those with poor baseline physical health, a poor prognosis, and advanced dementia. Antibiotics may be considered in palliative (not just curative) treatment of pneumonia; but for many patients, meticulous supportive care may be the most appropriate option, and this approach can achieve a comfortable death without the need for antibiotics or their potential burdens.

Cardiopulmonary Resuscitation

Cardiopulmonary resuscitation (CPR) is known to have a poor success rate in patients with advanced incurable illness and poor general health, such as those with advanced dementia.^{16,27,30} It also carries a risk of complications and harmful side effects (rib fracture, for example).^{8,16}

Do-not-resuscitate orders only apply to resuscitation and not other potential treatments¹²; discussions about resuscitation should therefore be placed in the context of other life-sustaining treatments such as artificial hydration and nutrition and antibiotics. Equally, CPR should not

be described to patients in these terms: “Would you want us to do everything?” This statement implies that not providing CPR is doing nothing. Some patients may not wish to be given the details or to make decisions about CPR themselves, and this should be respected.^{16,31}

For patients who do not have the capacity to make such decisions and who do not have an advance directive or proxy decision maker, important information to consider includes the likelihood of successfully restarting the patient’s heart and breathing; the patient’s known, or ascertainable, wishes; the patient’s current quality of life and predicted quality of life after resuscitation; and the patient’s human rights, both the right to life but also the right to be free from degrading treatment.³² For the majority of patients with advanced dementia, CPR is unlikely to be appropriate due to the low probability of success of the procedure, the quality of life before and after CPR, and the potential to do harm.³³

Artificial Feeding

Patients with advanced dementia commonly develop difficulties eating, often at a stage when they have become bedridden and dependent for activities

of daily living.^{34–36} Difficulties with oral nutrition may relate to poor appetite, trouble managing a food bolus once in the mouth (oral phase dysphagia), or aspiration when swallowing.^{21,34,36}

In this situation, artificial nutrition via a percutaneous endoscopic gastrostomy (PEG) may be considered. Any perceived potential benefits (e.g., the prevention of aspiration pneumonia or improved survival) must be balanced against any potential harm of the procedure, such as the immediate mortality of 0–2%, preoperative mortality of 6–25%,³⁶ tube leakage (13–20%), local infection (4–16%), and more serious complications such as perforation.^{34,36} Furthermore, when tube feeding is used to replace oral feeding, patients are deprived of the pleasure that comes from eating and the social interaction that occurs with mealtimes.

Aspiration Pneumonia

Regurgitation of gastric contents and the risk of aspiration pneumonia do not actually appear to be reduced in patients artificially fed via a PEG and may even be increased.^{13,21,34–36} This may be because artificial feeding via a PEG cannot be expected to prevent aspiration of oral secretions, and the procedure of placing

Table 1: Initiating and Continuing or Withdrawing and Withholding Treatment—Examples of Clinical Situations

Situations Where Treatment May Be Initiated or Continued	Situations Where Treatment May Be Withheld or Withdrawn
When the patient is stable or improving	When the primary goal of care is palliation of symptoms
When the risk/benefit ratio is unclear or the prognosis uncertain (consider a trial of the intervention and withdraw if little or no benefit)	When the patient is suffering and the intervention is merely prolonging the dying process or causing suffering
As a short-term intervention in patients with an acute, potentially reversible illness (e.g., antibiotics for urinary tract infection)	When the intervention may cause complications (e.g., agitation, the need for restraint)
When the quality of life is good, as defined by the patient	When the risks exceed the benefits (e.g., intravenous fluids in a patient with severe congestive heart failure)
When the intervention may maintain or improve quality of life (e.g., fluid replacement for agitation and restlessness due to dehydration)	When the quality of life is poor, as defined by the patient
	When the intervention is unlikely to improve quality of life

Source: Adapted from Ackermann R, 2000.¹²

Key Points

Decisions whether to withhold or withdraw life-sustaining treatment should balance the potential benefit of any intervention, the potential harm, and the patient's wishes (or previously expressed preferences) based on the ethical principles of autonomy, beneficence, nonmaleficence, and justice.

Patients who do not have the mental capacity to make informed decisions should still be involved in the decision-making process as far as is practical and appropriate.

Current research suggests that artificial feeding, antibiotics for pneumonia, and cardiopulmonary resuscitation are unlikely to be appropriate for most patients with advanced dementia.

When there is disagreement around withdrawing/withholding treatment, a second independent medical review or legal opinion should be sought.

Estimating the prognosis in dementia patients is difficult; the "surprise question" is a simple method to help physicians identify patients with a short prognosis.

the gastrostomy tube itself may actually reduce the effectiveness of the lower esophageal sphincter and increase the risk of gastroesophageal reflux.^{34,35}

Malnutrition

Despite the presumption that artificial feeding may prevent or correct consequences of malnutrition such as pressure ulcers and infection,³⁵ research has not shown that the provision of increased nutrients to patients with abnormal markers of nutritional state (e.g., low serum albumin) has any positive effect.^{13,34,35}

Survival

There does not appear to be any survival advantage for dementia patients who are

artificially fed via a PEG compared with those who are fed by hand (even after adjusting for other factors such as age, functional state, and cognitive state).^{21,35,36}

Pressure Ulcers and Infection Risk

Artificial feeding has not been found to correlate with the healing of pressure sores or with the prevention of the development of new pressure sores.^{21,34,36} In fact, it may be associated with an increased infection rate as a complication of the procedure.^{13,34,36}

Functional Status

Research has not found any improvement in function (e.g., as measured by the Functional Independence Measurement scale) following PEG placement.^{21,34,36}

Alternatives to Artificial Feeding

An alternative option to artificial feeding in this patient group may include reviewing and reducing the use of medications that might be contributing to difficulty eating, such as anticholinergics. Also, simple measures can be taken, such as offering preferred foods, providing strong flavours, and using supplements.³⁶

In individuals with advanced dementia for whom the prognosis is poor, withholding food seems unethical.^{21,34} In such patients, a suitable approach may be to offer the patient food of a modified consistency and with aspiration precautions (e.g., hand feeding, keeping the bolus size to <5 mL, and verbal reminders to swallow) but acknowledging that the patients could aspirate even on their own saliva.³⁶ Whereas tube feeding may decrease social interaction at meal times, hand feeding involves close interaction between the patient and caregiver.³⁴

In summary, patients with advanced dementia may be managed by continued oral feeding, letting the natural course of their disease define the extent and duration of feeding.³⁴ Since eating is typically among the last activities of daily living to become impaired, difficulty with eating is itself an indication that the person has entered the final phase of the illness.²¹

Conclusion

Dementia is a progressive incurable illness. A number of challenging situations arise in these patients in terms of withholding or withdrawing life-sustaining treatment. Current research provides principles on which the clinician can base decision making, but ultimately all decisions to withhold or withdraw treatment must be based on an individual assessment of each patient in consultation with the health care team and the patient's relatives. Patients without capacity should still be involved in decision making as far as possible. Advance directives allow patients to make such decisions while they still have the capacity to do so, and therefore provide them some control over their care at the end of life.



No competing financial interests declared.

Clinical Pearls

In day-to-day clinical practice, the surprise question "Would you be surprised if this patient were to die in the next 6-12 months?" is a useful, simple, and accepted way of identifying patients with a limited prognosis in whom end-of-life decisions need to be made.

Patients are unlikely to have mental capacity to make a decision if you answer no to one or more of the following simple questions: (1) Can they understand the information relating to the decision? (2) Can they retain it? (3) Can they demonstrate they are considering the pros and cons in making their decision? and (4) Can they communicate their decision?

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