

# A Consensus-Based Approach To Providing Palliative Care to Patients Who Lack Decision-Making Capacity

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Making palliative care decisions for a patient who lacks decision-making capacity presents several challenges. Other people, such as family and caregivers, must choose for the patient. The goals and values of these decision makers may conflict with those of each other and with those of the patient, who now lacks the capacity to participate in the decision. This paper presents a case study of a patient with severe Alzheimer disease who has two common clinical problems: neurogenic dysphagia and aspiration pneumonia. The case study describes a consensus-based decision-making strategy that keeps what is known about the patient's wishes and values in the foreground but also expects guidance from the physician and elicits input from family members and other people who care for and have knowledge about the patient. The steps of this process, including key clinical prompts and potential transition statements, are outlined and described. The overall goal of the case commentary is to demonstrate that physicians can guide a highly emotional and personal process in a structured manner that has meaning for the patient, family, physician, and other caregivers.

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As we grow older the world becomes stranger, the pattern more complicated of dead and living.

—T.S. Eliot, "East Coker"

**M**rs. B. is a 73-year-old woman with severe Alzheimer disease. She is a retired schoolteacher and has a husband and daughter. For the past 3 years she has lived in a nursing home and requires assistance with all of her basic activities of daily living. Mr. B. visits her daily and feeds her lunch. In the past several weeks, she has taken longer to finish small portions. At times, she coughs while being fed. One morning after breakfast, Mrs. B. develops agitation, a cough, and a temperature of 100.3 °F.

Palliative care is designed to relieve a patient's suffering in order to maximize dignity and quality of life (1). Respect for a patient's autonomous choices is a foundation of western bioethics, but a patient with severe dementia can no longer decide whether to receive predominantly palliative care or to continue potentially life-prolonging therapy. Other people, such as family members and caregivers, must choose for the patient. The goals and values of these decision makers may conflict with those of each other and with those of the patient, who now lacks the capacity to participate in the decision. Conflicts are especially likely in decision making about two common clinical problems: aspiration pneumonia and neurogenic dysphagia. These problems engage deep values about feeding, starvation, and the meaning of care for a patient with severe dementia (2). Furthermore, a patient's residence in a nursing home introduces additional problems related to regulations governing the management of a patient's weight loss and nutrition (3). How can a busy internist address these problems in a manner that achieves consensus among decision makers? This case study illustrates an approach to developing palliative care plans for patients with severe dementia.

*At a meeting with Mr. B. and the daughter, the physician explains that aspiration pneumonia is a common problem in severe stages of dementia caused by irreversible and progressive loss of the ability to chew and swallow food. Mr. B. agrees that his wife has had trouble eating, and he describes how on some days she eats very little of even her favorite foods.*

*To prompt the family to tell more about their perception of how Mrs. B. has changed, the physician asks, "I know that Mrs. B. was diagnosed with Alz-*

**Table 1. The Core Principles with Which To Plan Palliative Care for Patients Who Lack Decision-Making Capacity**

Structure the decision making as a consensus-building process grounded in dialogue among proxy, other close family members, physician, and immediate caregivers.

The goal is to achieve consensus about diagnosis and prognosis; the benefits and burdens of different treatment options; and the meaning of emotionally charged terms, such as "starvation," "suffering," "quality of life," "feeding," and "dying."

Decisions should be based on: 1) the patient's preferences and 2) a balance of the burdens and benefits of each option in terms of its ability to relieve suffering and maximize dignity and quality of life.

Palliative care should be offered whether life-prolonging measures are initiated or the patient is treated with comfort measures only.

*heimer's over 7 years ago, but I have only known her for the last few months. Can you tell me how she seems to you now, and how things have changed compared to when she was first admitted?"*

*The family's story begins with a summer vacation cut short when Mrs. B. fell and was hospitalized for 10 days. She never fully recovered and subsequently experienced a progressive loss of function over the next 7 years. The physician responds to the story by saying, "I think I have a better understanding about how things have changed over the past few years. It sounds like both you and she have done the best you could through a difficult situation. You know that Mrs. B. has an incurable, progressive, and ultimately fatal disease. I can't say for sure when she'll die of her Alzheimer's disease, but given its severity, we shouldn't be surprised when she does. Even if she does recover from this pneumonia, she will not recover her swallowing function. Recognizing this, we ought to care for her in a way that makes us confident that after she's gone, we can say she was treated with dignity and respect.*

*"I use two principles to help think through the decisions we face. First, consider your understanding of what Mrs. B. would want if she could tell us. Second, we should balance the burdens and benefits of each option in terms of its ability to relieve her suffering and maximize her dignity and the quality of her remaining life."*

This narrative begins an emotional and meaningful dialogue that should lead to a consensus about the best way to care for Mrs. B. given her clinical circumstances. This consensus-based approach is distinct from a discussion in which individuals simply share their opinions, but there is no genuine attempt to reconcile their differences. The process and pitfalls of consensus building will vary depending on the patient's clinical condition, the family dynamics, and the level of preexisting trust or conflict in the physician-patient-family relationships. Nonetheless, the physician can guide this dialogue by using goals and steps that are outlined in **Tables 1 and 2** and are discussed below.

The physician's first step was to identify potential decision makers. If Mrs. B. had completed an advance directive that included a durable power of attorney for health care, that person would be her main representative in decision making. However, most patients in nursing homes do not have advance directives (4), and even when they do, the contribution of others, such as family and formal caregivers, can greatly assist the designated surrogate in decision making (5, 6). Even if the patient doesn't have an advance directive, the physician can turn to close family members and others who know the patient well with the assurance that the family's standing to serve as surrogate decision makers is established by both case and statutory law (7). Except in cases in which the patient has no family or has a family that does not represent the patient's best interests, the physician is under no moral or legal authority to seek a guardian (a forthcoming paper from the American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus Panel will focus on legal issues) (7, 8).

After identifying the decision makers and clarifying Mrs. B.'s diagnoses, the physician then encouraged them to describe the course of Mrs. B.'s dementia by asking the husband and daughter how Mrs. B. has changed. The purpose of this dialogue is to achieve a consensus among decision makers about the patient's current disease state, prognosis, quality of life, and previously stated values (5). This

**Table 2. Steps to Providing Palliative Care to Patients Who Lack Decision-Making Capacity**

Step	Representative Quote To Achieve Step
1. Identify the main participants in the decision making	"We need to make some decisions about the care of your wife. Is everyone here who could help us think through what we should do?"
2. A. Allow the participants to narrate how the patient has come to this stage of illness B. In cases where the physician has an extended relationship with the patient and family	"Can you tell me how she's changed, how things have gone for all of you?"  "I know I've been caring for your wife for many years, but it helps me if you can tell me how she's changed, how things have gone for each of you?"
3. Teach the decision makers about the expected clinical course of the patient's disease	"Your wife has an incurable, progressive, and ultimately fatal disease. I can't say for sure when she'll die of her Alzheimer disease, but given its severity, we shouldn't be surprised when she does."
4. Advocate for the patient's quality of life and dignity	"We ought to care for her in a way that makes us confident that after she's gone, we can say she was treated with dignity and respect."
5. Provide guidance on the basis of existing data and clinical experience	"For patients like Mrs. B., feeding with a tube does not significantly reduce the risk for pneumonia. On the basis of my experience, a speech therapist can give us some useful hints on ways to feed her that will allow her to continue to eat by mouth."

sharing of narratives may expose important differences in beliefs and understandings in any of these domains that must be reconciled before consensus-based decision making can proceed. The more the physician understands these various perceptions, the more likely he or she is to develop a plan that will respect Mrs. B. as a person. Even when the physician has a long-term relationship with the family and patient, this step in consensus building should not be skipped. Research showing that physicians often inadequately understand their patients' preferences for health care supports this point (9–11).

The next step in consensus building is to begin a dialogue about prognosis and about the potential role of palliative care. This was done with the phrase that began "Unfortunately, Mrs. B. has an incurable, progressive, and ultimately fatal disease. . . ." Although this physician believes strongly in a palliative approach that includes pain and symptom management and avoidance of invasive treatments for patients with severe Alzheimer disease, he must respect that others may value an approach in which available medical technology must always be used to prolong life. Before a consensus about what might be included in a palliative approach for a particular patient is possible, the physician must learn what "treated with dignity and respect" means in this family.

Finally, the physician guided the family on ethical standards for decision making: 1) Consider what is known of the patient's wishes and preferences given her current condition (for example, a living will or potentially relevant statements made when the patient was competent) and 2) balance the burdens and benefits of each option in terms of its ability to maximize Mrs. B.'s dignity and quality of life. Deciding how to care for Mrs. B. by using only a rigid understanding of her past preferences may fail to respect her present circumstances (12). Achieving consensus about her current quality of life, although a subjective and personal process, incorporates the family's, physician's, and health care team's perceptions of her circumstances into what is known about her past preferences and values.

Missing from these recommendations to the family is an exclusive appeal to futility as grounds for decision making. *Futility* refers to the claim that no desirable benefit can be achieved by potentially life-prolonging treatment (13). Physicians frequently cite futility as their reason for terminating further treatment (14). Although the concept of "medical futility" exists to communicate extremely poor prognosis, it can also inadvertently convey an unequivocal, unilateral, and negative judgment about a patient's quality of life without leading to an explicit discussion of these issues from the differing perspectives of physicians and families. Furthermore, too fre-

quently, the term connotes that "nothing more can be done" for a patient, that further intervention would be meaningless, or that her life is of no current value. Therefore, a physician who relies exclusively on futility as a reason to pursue palliative care can obscure an honest discussion of how people understand and value the patient's continued existence and of the range of possibilities for palliative and life-prolonging interventions.

*Mr. B. and the daughter agree that Mrs. B. never expressed clear preferences about how she should be treated. The physician reassures them that they can still work on a plan. He outlines the options, including transfer to the hospital or staying at the nursing home with or without antibiotic therapy, and explains his view of their benefits and burdens: "A helpful way to think through these choices is to come to some consensus upon her current quality of life, and then decide what options will best maximize it."*

*In the ensuing discussion, Mrs. B.'s daughter and the physician state that they feel that Mrs. B.'s quality of life is poor because she cannot communicate or move around, but the husband disagrees. "I know she still hears me and understands me. I can see it in her eyes, when I bring her food from home." The daughter begins to cry and says that her mother would not want to live the way she is. Again, the husband disagrees: "You're not there every day! I am!" This common conflict challenges the consensus-building process.*

*The physician looks for common ground by asking them: "If she gets worse, if she can't recognize you or starts to suffer more, do we all agree that we should focus purely on her comfort and that even antibiotics would be too invasive?" The husband starts to cry and is comforted by the daughter. They both nod in agreement.*

*The physician then proposes a compromise plan. "Mr. B., your visits are important. I recommend that we keep her here at the nursing home where you can visit her as much as possible; we can simultaneously provide antibiotics and try our best to keep her comfortable. If she deteriorates, our focus can shift exclusively to relieving her symptoms and minimizing her immediate suffering. I strongly recommend against providing cardiopulmonary resuscitation should she have a cardiac arrest, since I don't think it would work and it would only add to her suffering."*

*The family agrees that the plan strikes a proper balance between benefits and burdens, giving her a chance of recovery without subjecting her to a foreign environment or overly harsh treatments.*

This decision-making process exposed two common features of caring for patients with severe dementia. First, clear information about the patient's wishes is typically unavailable. Second, decision makers often have differing assessments of the patient's preferences and quality of life (15). In this

case, the daughter and the physician thought that Mrs. B. had a poor quality of life and were concerned that hospitalization and even antibiotics might further decrease her quality of life. The husband disagreed. They all were genuinely trying to act in Mrs. B.'s best interests without clear information about her preferences. They achieved compromise with the decision to give Mrs. B. a therapeutic trial of antibiotics at the nursing home.

Dialogue is essential for achieving consensus on a course of action that is responsive to both past and present patient realities, as well as to the concerns and priorities of the family (5, 6, 16). The goal of dialogue is not to provoke conflict but to clarify common ground and differences and lead to better appreciation of the meaning of the decision for the patient and her family (5, 17). This approach to decision making is grounded in narrative theory that unifies the clinical and moral dimensions of medicine (18, 19). Clinical medicine is grounded in a series of stories told and interpreted from a variety of perspectives. The physician usually interprets these stories, using the science of clinical medicine, to develop a diagnostic and therapeutic plan. These same stories can be simultaneously used to understand the patient's values, goals, and meanings of illness, which should guide the personal and moral sides of the same process. Narrative theory was put into practice when the physician prompted Mr. B. and his daughter to describe their perception of Mrs. B.'s current condition, as well as how she has changed over recent years. The physician also shared his own perceptions. Reconciling the perceptions conveyed in these stories decisively shaped the process of medical decision making on Mrs. B.'s behalf.

This theory has some limitations. Consensus occurs in the context of choices. However, in the care of patients with severe dementia who live in nursing homes, local customs, beliefs, and systems of care can limit reasonable choices. For example, long-term care regulations are often wrongly believed to require that all residents with neurogenic dysphagia receive artificial nutrition and hydration. Surrogate decision-making laws are often misinterpreted to require a legally designated guardian for noncompetent patients who lack an advance directive (3). Although a few state laws (in Missouri and New York) require a high degree of proof of a surrogate decision maker's knowledge of a patient's wishes to allow the surrogate to withhold or withdraw artificial hydration or nutrition from noncompetent patients, most states support the legal right of surrogate decision makers to refuse any and all unwanted medical treatments when this decision is based on a consensus of the patient's wishes and best interests (3). In addition to legal inconsistencies and misper-

ceptions, both health care systems and local community practices powerfully influence choices and decisions. For example, in the same community, two otherwise high-quality nursing homes may have dramatically different rates of enteral feeding for patients with severe dementia. Research shows that large national variations in the rates of dying at home correlate with regional inpatient bed availability, not with patient or family preferences (20).

An additional practical concern of a busy internist is that these dialogues take time. No empirical data compare the time requirements of this method with those of other decision-making strategies. But the investments in mutual understanding and trust building should ultimately improve decision making, promote higher-quality care, and prevent conflict as the patient's illness progresses.

*"What happens if I feed her?" asks Mr. B. "Isn't she going to choke or get a worse pneumonia? Should we feed her by a tube or in the vein?"*

Mr. B.'s questions describe a typical decision-making cascade. Because oral feeding is thought to put the patient at risk for aspiration pneumonia, it is stopped, and mechanical feeding, either intravenously or enterally, is started so that the patient does not aspirate or starve.

In addition to exploring the benefits and burdens of these technical interventions, the physician's duty is to teach the family about palliative care options for patients with neurogenic dysphagia caused by severe dementia who develop aspiration pneumonia. The decision to use or not to use a feeding tube is not a *prima facie* determinant of the quality of palliative care for a patient with severe dementia. Although no randomized comparison of oral versus enteral feeding has been reported, the available studies suggest that enteral feeding does not significantly reduce, and may even increase, the risk for aspiration pneumonia (21, 22). In addition, enteral feeding may not prevent weight loss or the progression of pressure ulcers (23, 24) and is associated with substantial 1-year mortality rates (25). Finally, a longitudinal cohort study (26) suggests that neurogenic dysphagia and common nutritional complications of severe dementia can be managed by careful oral feeding. Given these data, the decision to use a feeding tube is best viewed as a personal choice based on deep values about the meaning of using a feeding tube or of continued oral feeding.

*The physician explains that a feeding tube will allow the delivery of adequate nutrition and hydration for a woman of Mrs. B.'s age and weight, but it may not improve the quality or length of her life or prevent further aspiration. It may also deprive her of the tastes, smells, and touches of normal eating. He appeals to the family to recall how they just made the decision to care for Mrs. B.'s pneumonia. The key issue was the*

pleasure Mrs. B. received from her husband's daily visits and the food that he gave her.

The husband becomes agitated. "I just can't starve her, watch her starve, if that's what you're saying." He begins to weep.

"But Dad, she eats what she wants. No one's saying don't feed her. It's just don't force-feed her."

"But how will we know she's hungry?" he asks.

The physician offers a suggestion. "Her eating and your feeding her is one of the few meaningful activities that she has left. I think you both agree that we ought to at least allow her to try some food by mouth. Perhaps a speech therapist can give you some useful hints on feeding your wife. The issue of how best to feed your wife doesn't need to be made now. Let's take a few days and see how she does with both the pneumonia and the feeding. In between, don't hesitate to call me with any questions."

The dialogue has again reached a point of conflict. **Table 3** lists some general ways to achieve common ground. In this case, the physician presents information about some of the burdens of enteral feeding, and some of the benefits of continued oral feeding that had not been considered by the family. He then proposes a short-term trial of oral feeding, with the help of a speech therapist, while simultaneously not precluding the possibility of enteral feeding in the future. In negotiating terms, he has proposed a compromise solution that avoids a power conflict and allows everyone's interests to be represented.

Two days later, the husband and daughter return. The husband explains, "I met with that therapist and she showed me how to get her to eat a whole container of sherbet that she likes. We talked with our minister. I think we're going to keep it natural like that for now."

Mrs. B. gradually recovers from the pneumonia after several days that entail considerable physical distress (cough, respiratory distress, fever, and agitation). In addition to the oral antibiotics, her symptoms were palliated with opioids, humidified oxygen, nebulizers, antipyretic agents, and low-dose antipsychotic agents.

Several months pass. Mrs. B. is now unable to use a straw. Her intake of spoon-fed fluids and food is scant. Her husband worries that she will die of starvation. He and the daughter reapproach the physician for advice about how to proceed.

The physician, Mr. B., Mrs. B.'s daughter, and their minister review Mrs. B.'s life and the recent events. After some discussion the physician says: "Her Alzheimer disease has progressed to the point where she's dying. I believe we ought to come up with a plan that minimizes her immediate suffering and maximizes her dignity and her quality of life."

A vigorous discussion follows. Eating was the one meaningful activity that remained in Mrs. B.'s life, but

**Table 3. What To Do If No Consensus Emerges**

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Postpone the decision making and recommend that the participants take time to think about and discuss key issues.
Understand and separate from each person's perspective the goals of medical care and the treatment choices to achieve these goals.
Invent new solutions (for example, a time-limited trial rather than an all-or-nothing solution).
Avoid power struggles or personalizing the conflict.
Call in a third party (for example, trusted clergy, ethics consult, or palliative care consult).
Don't violate fundamental values of the patient, family, or physician.

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artificial feeding cannot serve the same function. Without that activity, the husband now believes that her quality of life is too poor to warrant the burdens of a feeding tube. Their minister agrees that a feeding tube would only prolong her suffering at this point. A plan is agreed upon to provide comfort measures only. She will be offered tastes and smells of her favorite foods and drinks; mouth and skin hygiene; lots of human contact, including repositioning and massage; but no enteral or intravenous nutrition or hydration.

After 7 days, Mrs. B. dies.

## Discussion

This case presents several common challenges to the practice of palliative care for patients with severe dementia. Mrs. B. could not speak for herself and, like most Americans, had not completed an advance directive. Even if she had, the preferences she expressed when competent may well have been indeterminate guides for managing her actual problems. She could not tell us whether she was suffering or describe her quality of life. The meaning of her signs and symptoms had to be interpreted. Furthermore, as a wife, mother, patient, and resident of a nursing home, she lived in a diverse community that had different views about what ought to be done for her. Finally, her problems included dementia complicated by aspiration pneumonia and severe dysphagia. No randomized, controlled studies guide the provision of oral versus enteral feeding under these circumstances (21–24). Despite this lack of evidence, those who care for and care about these patients must make decisions.

This case illustrates a palliative care strategy grounded in the theory that decisions for patients such as Mrs. B. are the result of dialogue and consensus building. The physician's initial investment of time may minimize the time and effort needed for future decisions. The physician's duty is to teach all participants that Mrs. B. has a chronic, irreversible, and ultimately fatal disease but also to learn from these participants about Mrs. B.'s values and quality of life. This frames decisions about hospitalization, antibiotics, and enteral nutritional sup-

port as medical choices that ultimately shape the way she will live the last phase of her life.

As a result of this dialogue, a family may decide that continued efforts to prolong life are critical regardless of the severity of the patient's disease. Principles of negotiation are often useful under these circumstances (Table 3). In general, physicians should guide the process because of their familiarity with medical processes and prognoses, but the surrogate decision makers must try to represent the patient's voice. Differences should be explored through dialogue that focuses on the patient's best interests and seeks common ground. Except when decisions seem to clearly violate the patient's best interests or prior wishes, the family has the final say in representing the patient in decision making. Families have to live with themselves and their role in these decisions long after the patient has died.

Conversely, some medical practitioners or long-term care institutions see their primary job as prolonging life under all clinical circumstances because of religious principles or personal training. These practitioners or institutions should make their philosophy known from the outset, especially if they feel obligated to override the values and wishes of patients and families, because they will be unable to pursue this consensus-based approach.

The meaning of suffering is personal and subjective. Evaluating the suffering of patients with dementia who cannot speak for themselves is inherently challenging. Even when suffering is recognized, its relief may be relegated in the pursuit of another goal, such as the preservation of life at all costs or hope for a miraculous cure. Yet through the process of repeatedly listening to the perspectives of each participant and involving the participants in a consensus-based interaction, decisions that respect the patient's dignity and quality of life can generally be achieved.

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