

# END-OF-LIFE PLANNING: HIGHLIGHTING A MISSING HEALTH CARE POLICY

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Recent legislative proposals have sparked conversations and debate regarding end-of-life decision-making. Advance care plans provide potential benefits to society and the individual, in both cost savings and enhanced quality of care at the end of life. End-of-life care planning can be encouraged through enhanced reimbursement for patient counseling, interstate portability of advanced care plans, and a requirement that health care providers and insurance plans offer advance care planning information. Health care policies would do well to encourage a model that empowers individuals to develop instructions for their end-of-life care in concert with their loved ones and personal health care providers.

FEATURE

## INTRODUCTION

At the time of the writing of this piece, health care reform proposals, including H.R. 3200, America's Affordable Health Choices Act of 2009, have placed a national spotlight on end-of-life decision-making. H.R. 3200 proposes that Americans be counseled periodically on "advance care planning" and the care options available to them at the end of life.[1] These proposals are motivated by concerns about high-cost end-of-life care that is not necessarily guaranteed to improve patient quality of life.[2] While professional medical organizations and practitioners have concluded that advance care planning should be encouraged among physicians and patients alike, this health care reform provision has been erroneously described as "death panels" for seniors, and some argue that it would ration health care for the elderly and allow government to play a role in a private decision-making process.[3,4]

This article examines how advance care planning encourages ethical decision-making, improves health care quality, and reduces medical costs. The author discusses barriers to public policy in promoting advance care planning and suggests policy solutions including improving Medicare reimbursement, enhancing interstate recognition of advance care plans, and mandating advance care plan discussions as a requirement of physician participation in Medicare.

### *What is Advance Care Planning?*

Advance care planning is a largely self-directed process which allows an individual to identify and communicate, in ad-

vance, the types of medical treatment and interventions he or she desires at the end of life in the event of a situation in which he or she cannot directly make those wishes known. The result of the planning process is often a written document called an advance directive or an advance care plan; this written document directs medical professionals' actions at the end of a patient's life and prevents unilateral, end-of-life decision-making by physicians and the government. Advance directives also serve to ease decision-making for family members who otherwise might find themselves called upon to make difficult choices about continuing or stopping care for a loved one.

Advance directives typically include a proxy designation or durable power of attorney, which specifies a surrogate who will speak for the patient when he or she cannot. In U.S. hospitals, a health care provider is required to provide "informed consent," adequately informing a patient or surrogate of the risks and benefits of any proposed treatment or procedure.[7] An incapacitated individual without a surrogate to make decisions for him or her is not able to refuse treatment if a health care provider believes the treatment to be beneficial to the patient.[8]

Advance directives also include a living will or health care directive, a written declaration specifying what types of treatments may be given to the patient in the event of a debilitating illness.[5,6] Even if a surrogate has been designated, determining a patient's wishes without a prior written declaration is complicated at best. The combination of a designated surrogate and a written health care directive is the most effective way to ensure one's end-of-life wishes are fulfilled.

### Box 1: An Advance Care Plan in Action

The following example illustrates how an Advance Care Plan can improve end-of-life decision-making as well as patient and family outcomes.

#### The Difficult End-of-Life Decision

Seventy-seven-year-old Mr. Smith has lung disease and dementia. He is admitted to the intensive-care unit (ICU) following surgery for suspected colon cancer. However, doctors find that the cancer had spread throughout his colon, leaving no hope of a medical or surgical cure. Mr. Smith is on a ventilator due to his chronic lung disease and has been given less than two months to live. He is unable to make decisions for himself and his remaining family cannot agree on a course of action.

#### The Outcome without an Advance Care Plan

Since his family cannot agree and his wishes are not known, Mr. Smith remains in the ICU on a ventilator. His other body systems start to fail and he contracts a severe pneumonia. He continues to live in the ICU for the next month. He finally has a cardiac arrest from which he is unable to be resuscitated.

#### The Importance of an Advance Care Plan

With an Advance Care Plan, Mr. Smith has previously, clearly stated that he does not want to be sustained on life support equipment should he be diagnosed with a terminal illness and unable to make decisions for himself. His breathing tube and ventilator are discontinued and he is moved to hospice care. His pain is controlled and he dies within a week. His family is able to spend his last moments with him without disagreement and does not bear the pain and responsibility of making end-of-life decisions.

### ADVANCE CARE PLANNING PROMOTES HIGH QUALITY CARE

Advance care planning outlines the wishes of the patient regarding the initiation and continuance of life-supporting measures. A qualified health care provider can deem further care of a patient medically futile when subsequent treatments will be of no immediate or long-term benefit.[9,10] When considering such decisions, it is recommended that providers work in cooperation with the patient's family. Without an advance care plan, however, an individual health care provider may take the dominant role in determining when to prolong, decrease, or even end life-supporting medical treatment. Care is improved and families are more satisfied with outcomes when they are involved in the decision-making process.[11,5]

An advance care plan can ease the transition to palliative care, which provides comfort care and support services for the individual who has little hope of survival and may be experiencing pain or discomfort due to illness. Palliative care services can improve both patient and caregiver quality of life, and often include family support services, pain management, skilled nursing care, and realistic goal-setting designed to achieve comfort and maintain dignity for patients in the final days or months of life.[12,13] Advance care planning eases the adoption of palliative care services by clearly stating a patient's preference for this type of treatment at a certain point. A patient can state a wish to avoid a lengthy stay in an intensive care unit (ICU), effectively shifting the focus of care onto pain management and preservation of dignity informed by the patient's own wishes.

### ADVANCE CARE PLANNING REDUCES END-OF-LIFE HEALTH CARE COSTS

Advance care planning has the potential to reduce personal and societal health care costs by reducing hospital and ICU lengths of stay. Patients and their families who find themselves in an ICU setting at the end of life have to make difficult decisions regarding costly treatments and procedures. Last-year-of-life expenses often account for as much as a quarter of all medical expenses.[17] Advance care planning can serve to clarify steps in care and effectively avoid high-cost treatments which offer little hope of benefit. A significant cost reduction has been seen in the last week of life, for instance, in terminal cancer patients who had end-of-life conversations with their treating physicians.[18]

Patient care in the ICU is also complicated. The needs of the patients are variable and often the post-ICU trajectory is not predictable, resulting in an inefficient use of resources and an inability to standardize patient flow. [15] Palliative and hospice care are accepted as alternatives to further life-supporting treatments and can be administered in the hospital or the patient's home.[20] In-home hospice care results in lower costs and greater patient satisfaction at the end of life.[13] Examinations of palliative care and the use of advance directives has demonstrated that these services can provide a cost savings of between 25 and 40 percent in the last month of life.[21, 22]

Advance care planning prior to hospital admission, when the patient is able to think clearly and is under less stress, is preferable for rational decision-making.[19] Advance directives written before admission to the hospital are associated with

cost savings, but these plans, if delayed until the end of life in the hospital, have little effect on cost.[23]

## GUIDANCE FOR POLICY

Advance care planning and thoughtful end-of-life decision-making can have a substantial impact on patients, families and our health care system.[24] Barriers to the proliferation of advance care planning certainly exist. As mentioned above, current popular characterization of advance care planning is that government policy would create “death panels,” or committees tasked with judging an individual’s worthiness to live.[25] In fact, H.R. 3200 states only that planning should be periodically offered to patients by their health care provider and is not mandated. Furthermore, under this proposal no panel is formed; interactions occur among the health care provider, the patient, and the patient’s family if the patient so wishes.[1] Opponents of H.R. 3200 capitalize on the fear that government will be granted the discretion to step in and make end-of-life decisions in place of patient or family wishes. However, the goal of creating an advance care plan is to preserve patient autonomy, making clear a patient’s wishes for end-of-life treatment. The best policy approach to advance care planning will strongly encourage participation of health care providers, patients, and families in the creation of advance care plans. Some methods to achieve these results include:

### 1. Medicare should reimburse health care providers for time taken to assist patients with advance care planning.

Currently, Medicare does not reimburse physicians who provide information or counsel their patients on advance care planning. Billing and service codes to indicate whether or not a patient has an advance care plan exist, but are not currently utilized to bill for physician time spent counseling on advance care planning.[26] To encourage advance care planning, Medicare and all third party payers must financially recognize these important sessions between patient and health care provider. There is concern that such reimbursement from the government, through Medicare, will result in government control of the outcome of the advance care planning process. However, the cost savings and enhanced quality of end-of-life care associated with implementation of advance care planning likely outweigh these concerns.

### 2. Federal legislation should provide for interstate recognition of patients’ advance directives and current wishes.

At present, all 50 states and the District of Columbia have written legislation regarding advance directives.[27] However, only 42 states recognize advance directives from other states, and

interpretation of those directives may differ by state, jeopardizing patients’ ability to have their wishes carried out at the end of life.[28] In cases where directives are not available, patients’ stated wishes, clearly documented in the medical record, may serve to direct care at the end of life. At present, only 14 states consider documentation in the medical record a valid directive. [29] This standard is too limited and jeopardizes adherence to patients’ wishes.

### 3. Health policy should require that advance care options be discussed as a requirement for patient or physician participation in insurance programs, particularly Medicare.

One approach would involve counseling all patients who qualify for Medicare—those over 65 or with other specific conditions—on advanced care plans either upon enrollment, or within six months of the first visit to a primary care provider. Another approach would require participating health care providers to offer advance care planning guidance to every patient unless refused by the patient. This information would be offered alongside currently accepted patient education, such as nutrition and smoking cessation. Health plans would not require a patient to produce an advance care plan, but the guidance provided would create a mechanism by which every patient with insurance would be exposed to the importance of end-of-life planning.

## CONCLUSION

Fostering discussions about the end of life between the patient and health care provider will both strengthen that relationship and plant the seed for popular support of legislation to promote end-of-life care. Policy alone will not overcome society’s fear of death, but encouraging discussions between patients and health care providers about advance care will help patients and their families plan for the end-of-life process.

Federal policy to ensure that patients maintain their autonomy through the end of life, while simultaneously making the best use of finite health care resources and providing humane care, will not be simple to achieve or easy to enforce. Prior policies (both enacted and suggested), such as H.R. 3200 have laid the groundwork, but further efforts should focus on creating a model of decision-making for patients and families that encourages the participation of personal health care providers. [30] The federal government, physicians, and society as a whole are doing a disservice to the medical system and individual patients if they do not strongly encourage those patients to provide clear instructions for their own care at the end of life.

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## ENDNOTES

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