Advance directives allow patients to influence their medical care after they have lost decision-making capacity. As it is impossible to predict a life-threatening event, physicians should address advance directives with every patient during routine office visits. To make informed decisions, patients must understand their options, such as CPR and artificial nutrition and hydration. Similarly, physicians need to understand patients’ values and goals, in order to counsel proxy decision-makers and guide their patients’ care. Two office visits are recommended; experienced physicians can usually accomplish the initial conversation in less than 10 minutes and the follow-up in less than 5 minutes. Because opinions and circumstances change, these documents should be reviewed annually.


The use of advance care directives has received widespread public support, yet only 4 to 24% of Americans are estimated to have actually completed such documents. Patient education to increase the prevalence of advance directives has met with limited success. Studies suggest that although patients might be aware of advance directives, they want their physicians to be the ones to initiate discussions about end-of-life treatment decisions.

With whom should you discuss advance care planning? How does one initiate such difficult discussions? Where and when should these take place? What information should you provide to the patient for the making of important care decisions? In this article, we discuss some general guidelines for enhancing patient-physician communication about end-of-life care. We illustrate these guidelines with a case discussion involving a healthy patient at midlife.

Mr. Stevens: New patient in good health

seeing you for the first time last month for the purpose of establishing a new physician. Mr Stevens and his wife recently moved into your community when he relocated for his job as an office manager.

His only medical problems are mild hypertension, for which he takes a thiazide diuretic, and osteoarthritis of his knees, for which he takes an occasional ibuprofen. His laboratory test results from the initial visit are normal.

Although advance care planning is most relevant for persons facing life-threatening illnesses, it is impossible to predict when a previously healthy person may suffer an acute, life-threatening event. Thus, it is important to address advance directives with everyone.

Studies have shown that patients believe that the most appropriate time and setting for advance care planning is a routine office visit when they are healthy. Beginning the process then also allows you to obtain and understand wishes before a person’s decision-making capacity might be compromised.

Advance directives: What are the options?

Decisions regarding life-sustaining medical care are commonly made after patients have lost capacity to make such decisions.
Preventive maintenance for the midlife patient

The articles presented in this year’s “CME in GERIATRICS” series offer physicians an analysis of common problems in midlife—from ages 45 to 65. Experts in a variety of disciplines discuss timely clinical actions that can pay off for the patient and society in terms of wellness and functional vitality.

Series Editor Fredrick T. Sherman, MD, MSc, oversees the quality of the series and ensures that the articles are practical and useful for the primary care physicians who read GERIATRICS. Dr. Sherman is vice chairman for clinical affairs, department of geriatrics and adult development, Mount Sinai Medical Center, New York.

The Pace and William Black Post-Graduate School of the Mount Sinai School of Medicine (CUNY) is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to sponsor continuing medical education for physicians and designates this Continuing Medical Education activity for 1 hour in Category 1 of the Physician’s Recognition Award for the American Medical Association.

their autonomy and influence their medical care at such times. Advance directives are recognized by all states as legally binding expressions of patients’ wishes.

The federal Patient Self-Determination Act was implemented in 1991 to promote the use of these documents. It requires that all persons be given information regarding their right to establish advance directives upon admission to a hospital, nursing home, or other health care facility that receives Medicare or Medicaid funding.

There are two types of advance directive (table 1):

- “Living wills,” or treatment directives, are typically a series of instructions regarding the withholding and withdrawal (usually) or implementation of life-sustaining medical care (eg, intubation, cardiopulmonary resuscitation, artificial nutrition and hydration) in the event of terminal illness.

- Durable powers of attorney for health care, or proxy appointment, a specific agent to make decisions regarding their medical care in the event of future mental incapacity.

Health care proxies may offer certain advantages because of their inherent flexibility. That is, the health care proxy allows designated surrogates to guide medical treatment immediately after a patient loses decisional capacity, rather than simply in situations of terminal illness. Furthermore, proxy appointments eliminate the difficulty of translating generalized treatment directives to specific clinical situations and allow surrogates to influence medical treatment in situations that a living will might not address.

Nevertheless, proxies cannot direct medical care as the patient would have wanted, unless guidance has been provided through previous conversations or by means of a living will. Thus, health care proxies and living wills are not mutually exclusive but complementary. Having both dom-

where a patient has no fami-

member or friend to designate as proxy, their wishes can be com-
municated through a living will alone.

Consulting a lawyer is not necessary to make advance directive legal binding. They can be completed by your patient alone or with your assistance. State-specific forms are available through hospitals, governmental agencies, and private organizations (such as Choice in Dying, 200 Varick St, New York, NY 10014; phone 212 366-5540).

Initiating a discussion: Part of routine care

Mr. Stevens’ second office visit is an ideal time to start talking about advance care planning (table 2). A relationship between Mr. Stevens and the physician has been established, and initiating the discussion now places advance care planning in the context of routine medical care—akin to screening for colon cancer via stool guaiac.

Most patients do not expect a discussion about advance directives when they visit their physician for ordinary care. They might assume that an adverse change in their health has triggered this discussion. Emphasize that advance care planning is routine, and its purpose is to acknowledge, understand, and respect the patient’s wishes regarding medical care.

Here is a suggested approach:

Mr. Stevens, I like to talk with all my patients about planning for their future medical care in the event that they develop a serious illness. It is a way for me to ensure that my patients are cared for in a way that they
they might not be able to communicate and make decisions for themselves.

I think it is a good opportunity now, while you are in good health, to begin to think and talk about these issues. I do not anticipate or expect that anything will happen to you in the near future, but illness and accidents often occur unexpectedly. As your doctor, I would like to understand how you would want to be treated and with whom I should speak if I could not communicate with you. Have you thought about these issues before?1

Some patients might indicate they have already completed an advance directive. Plan to review it with them, inquire whether changes need to be made, and request a copy for the chart.

For patients without an advance directive, it might be helpful to inform them that you have completed one (assuming you have), despite being in good health. This would emphasize the importance of advance care planning and help to reassure them that this discussion is routine.1

Some patients may still be uncomfortable with the process, or they may desire a more paternalistic model of care. They might try to place the decision-making burden on you or someone else, using statements such as, “Whatever you think, Doc,” or, “Just talk to my family.”12 If this happens, emphasize to patients that it is their opinion that is most important. You might say:

Your family and I need to understand your thoughts on this, and we need to go through this together. I will be happy to give it is important for me to understand what you would want. There is nothing about your health that we have not already discussed; planning for the future is simply prudent for all people.11

Eliciting preferences, understanding values

An exchange of information is vital to advance care planning. For patients to make informed decisions, they must understand their current state of health and the options available to them if they become seriously ill. Similarly, physicians need to understand the values and goals of their patients in order to appropriately counsel proxy decision-makers and guide their patients’ care.

Thus, you need to talk about factors that are important to the patient, such as:

- spiritual, cultural, and personal values
- previous experiences with serious illness in themselves, their family, or friends
- things that might make life intolerable.

Provide patients with specific information about their present health status and concrete prognostic information. Clearly explain living wills and health care proxies, how they are utilized, and how they can be easily completed. For example:

Mr. Stevens, you suffer from high blood pressure, which has been well treated, but you are in otherwise excellent health. With continued care, there is no reason why you should not live a long, healthy, independent life. What does a healthy, independent life mean to you? Can you tell me a little bit about what makes life worth living for you?

Sometimes, people have very clear ideas as to what type of care they would want to receive if they were to become very ill or they were dying. Are there circumstances under which you would want treatment stopped or avoided, and can you tell me about these? Can
TABLE 2

Physician guidelines to advance directive discussion

WHEN
Initial office visit

RECOMMENDATION
Follow up on any routine medical care
Initiate discussion of advance directives
Review patient's health status and prognosis
Explain the need to plan future medical care
Durable power of attorney for healthcare
Living wills
Probe for patient's values, beliefs, experiences
Describe specific medical treatments
CPR (provide survival statistics, if requested)
Artificial nutrition and hydration
Explore patient's wishes and understanding of medical terms (eg, extraordinary measures)
Provide written forms and patient information
Encourage patient to invite proxies (spouse, family, and/or friend) to follow-up visit
Afterward, dictate and send a letter to patient, summarizing your discussion

Follow-up visit

Answer questions
Review patient's wishes, so they are understood by patient, physician, and proxies
Copy advance directive documents
Provide to patient and proxies
Attach to patient's chart
Emphasize patient control of decisions
Can be changed by the patient at any time
Should be reviewed annually

Source: Prepared for Geriatrics by Maria Torreola Carney, MD, and R. Sean Morrison, MD

under which you would consider life to be intolerable or not worth living (eg, advanced dementia or severe neurologic impairment, advanced cancer, persistent vegetative states)?

If patients have difficulty responding to these questions, it is sometimes helpful to ask about past experiences with family or friends who were seriously ill or dying and ask about their thoughts and emotions about these experiences.

Can you tell me about any experiences you have had with family or friends who were seriously ill or dying? What about their care did you agree or disagree with and why? What would you have wanted done if you were in their situations?

After you believe you have a basic understanding of the patient's values, briefly summarize this discussion so that you are both comfortable that a shared understanding has been achieved. Then prescription of specific medical treatment and an exploration of patient wishes regarding these procedures.

Making informed decisions: CPR, artificial nutrition

Although it is difficult to cover all potential treatments and scenarios, we suggest that you at least address the issues of cardiopulmonary resuscitation (CPR) and the use of artificial nutrition and hydration. Other issues that patients may want to address include the use of dialysis, long-term ventilatory care, and nursing home placement. The following is an ample description of CPR that can be provided to patients:

When a person's heart or lungs stop, manual pressure to the chest, artificial breathing, drugs through IVs, and electric shocks to the chest may restore heart functions. If the lungs do not work adequately, a machine called a ventilator can take over breathing and provide oxygen through a tube down the throat. In either case, transfer to an intensive care unit and prolonged hospital care will be required.12,13

Providing survival statistics on cardiopulmonary arrests can facilitate decision-making and should be shared with patients who request:

- For in-hospital arrests, 15% of patients survive to charge from the hospital.
- For long-term care arrests, 2% of patients survive to charge from the hospital.
- For patients who suffer arrest out-of-institution, 4 to 7 survive to discharge from the hospital. For those who survive to
crease in dependence, requiring extensive home care or institutionalization. A smaller percentage have severe mental impairment.14

Of course, survival is lower in patients with underlying conditions such as metastatic cancer, sepsis, and renal failure, compared with previously healthy patients, and this should be communicated to patients.

Decisions regarding artificial nutrition and hydration are sometimes more difficult, given the strong emotional and cultural issues associated with food and fluid. It is important for patients to understand exactly what the provision of artificial nutrition and hydration entails: what it is, the risks and benefits associated with it, how it differs from food and water, and the legal requirements that must be met before such therapy can be withheld or withdrawn.

Some states (eg, New York and Missouri) distinguish artificial nutrition and hydration from other forms of life-prolonging therapy. Their laws require a higher level of evidence of patients' prior wishes before this therapy can be withheld or withdrawn (eg, clear and convincing as opposed to reasonable evidence). Because of these requirements, patients' wishes should be clearly understood.

Explain that there are two means of providing artificial nutrition:

- Enteral nutrition or "tube feeding" is the provision of artificial nutrients and fluids by means of a tube inserted into the stomach via the nasal passages (nasogastric tubes) or percutaneously (percutaneous gastrostomy [PEG] tubes). This is the more common means of artificial nutrition.

- Parenteral nutrition is the provision of artificial nutrients by vein. This system is diseased and not functioning properly.

Enteral feeding is indicated in the short term to provide nutrition and hydration for seriously ill patients who are recovering the ability to eat, and in the long term to supplement oral feeding in patients unable to take in adequate nutrients to maintain or regain health or function.

Although tube feeding has been likened to ordinary care—the provision of food and water—this is not an accurate analogy. Unlike eating and drinking, tube feeding lacks the pleasurable oral stimuli associated with food and fluids. In addition, complications including pneumonia, erosion of mucosa, bleeding, diarrhea, electrolyte imbalance, and discomfort have been associated with gastrostomy tubes.15

Patients should be aware that dying without tube feeding is a natural process. There is no evidence that forgoing artificial nutrition and hydration imposes an additional burden or suffering on the patient at the end of life. Can-

Indeed, total cessation of caloric intake has been associated with sensations of euphoria.16 Thirst has been associated with the cessation of fluids, but this can usually be managed effectively with ice chips, mouth swabs, and lubricants.17

Customizing directives to patient preferences

Patients need to understand that they have control in this decision-making process. There may be certain procedures some individuals would want attempted under all circumstances or, conversely, certain treatments they would not want under any circumstances. These wishes need to be explored and specifically addressed.

For example, although patients may state that they would not want a specific procedure, does this apply to all circumstances? Would they want a trial of CPR or ventilator support if recovery to the previous level of mental and physical function was likely?

To avoid misunderstandings,
example, although it is common for patients to request that they receive no “extraordinary measures,” the definition of this term varies from patient to patient (e.g., many patients and religious groups do not consider tube feeding an extraordinary measure). Thus, it is critical to ask patients what they mean by extraordinary measures and what they consider ordinary care.

Finally, discuss alternatives to life-prolonging treatment (e.g., palliative or hospice care). Reassure patients that under all circumstances their pain will be treated, their symptoms managed, and their wishes followed.

**Proxy selection: Factors to consider**

The final step in advance care planning is the patient’s selection of a healthcare proxy, which can be a difficult decision. Factors to consider are the proxy’s personality, understanding of personal values, reliability, and accessibility.

A proxy must:

- be willing to act as a medical decision-maker on behalf of the patient, should it be necessary
- understand the patient’s values and wishes and act in accordance with those wishes, even if they differ from the proxy’s personal beliefs.

It is often helpful for patients to designate a primary proxy and a secondary proxy if the former is not available. Some patients may be uncomfortable designating one person as their agent and would prefer a group of family members to make a consensual decision about their health care in situations of decisional incapacity. As many states do not recognize family or group decision-making, counsel patients to designate one person as their proxy but to communicate to the family that this person’s role is to act and serve as a spokesperson for the group as a whole.

Ideally, it would be helpful to spread the advance care discussion over two visits allows for more efficient management of your time.

**Spreading the advance care discussion over two visits allows for more efficient management of your time**

include a patient’s proxy at the office visit when you begin discussing advance directives, involving a spouse, friend, or others who are close to the patient provides emotional support and facilitates communication of the patient’s wishes to their proxies.

In practice, however, it is often difficult—and therefore uncommon—to include the patient’s health care proxy in the initial meeting. This is unfortunate, as studies have shown that communication regarding wishes for future health care is poor between patients and their designated proxies. Not surprisingly, this leads to poor concordance between patient and proxy decisions when presented with case scenarios.

If the patient’s proxy is not present, emphasize how important it is for the patient to communicate their wishes to their proxy. Encourage the patient to bring their proxy to their next office visit, if possible. At this subsequent visit, you can review and summarize the advance care planning discussion, answer questions, clarify any areas of uncertainty, and formally complete the patient’s health care proxy and/or living will.

**The initial visit: Dialogue, education, and forms**

You could complete the advance directive discussion in one session but we recommend two office visits. This allows patients to evaluate the information, confer with others, and return to the follow-up appointment with questions. Give the time constraints in most offices, spreading the discussion over two visits also allows for more efficient management of your time.

After the initial session, it is useful to provide patients with:

- a brief written summary of your conversation for them to take home or a follow-up summary letter form (this letter, dictated immediately following the visit, is useful to confirm that adequate communication has occurred, as it can facilitate communication between patients and proxies)
- educational materials regarding advance directives from organizations such as Choice in Dying
- blank advance directive documents that the patient can examine and/or complete at home.

For most patients, the initial advance care planning discussion can be accomplished by experience physicians in less than 10 minutes and the follow-up conversation less than 5 minutes. Persons with less education or decreased cognition may need more time or more office sessions to structure the decisions.

**The follow-up visit: Recap, documentation**

At the follow-up visit, complete a documentation. Briefly review the patient’s wishes regarding care and proxy appointments, and as
answer any additional questions. Place completed, signed health care proxy forms and living wills in the patient's medical record. In our practice, we find it useful to flag charts with stickers identifying the name and telephone number of the patient's proxy. Give copies of the documents to the patient and their designated agent. Instruct patients to keep their advance directives accessible (eg, not in an attorney's office or safe deposit box) and to bring them if hospitalization is ever necessary. If their hospital of choice maintains a file of advance directives, encourage patients to use this resource.

Finally, reassure patients that they can express opinions, requests, and proxy appointments can be changed at any time. Indeed, because opinions may change, advance directives should be readdressed periodically.23 We recommend that you review them annually with your patients in conjunction with other health maintenance events (eg, physical exams, stool guaiac tests, mammography, or influenza vaccination). This review should include:

- A brief summary of the patient's health status
- Any changes in their clinical condition since the last review
- A summary of the patient's wishes and listing of proxy appointments
- An opportunity to address any new questions.

Advance directives should also be readdressed whenever a patient's clinical condition changes substantially, or they are admitted to a health care institution (eg, a hospital or nursing home).

Conclusion

There is a risk, however, that the discussion of treatment options and directives may be dominated by pamphlets and brochures.24 This can be avoided by integrating this discussion into the ongoing dialogue between physician and patient about the patient's health status and future.

Patients indicate that they want their doctors to initiate these discussions and to provide information that is understandable, accurate, and sensitively communicated. Physician-patient communication is enhanced when such discussions begin early in the clinical relationship and the decisions are periodically reviewed.25

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