

# EPEEC-O

Education in Palliative and End-of-life Care - Oncology

## **Participant's Handbook**

Module 13

## **Advance Care Planning**

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## Abstract

Advance care planning is the process of planning for future medical care, particularly for the event when the patient is unable to make his or her own decisions. It can balance the necessary focus on end-of-life planning with appropriate sources of optimism, especially if encompassed as part of the continuously adjusted goal planning discussions that guide a well-conducted care process. As with discussions about some other types of care goals, salient conversations should be conducted with the proxy decision maker present if at all possible. It is helpful to think of the process as a stepwise approach. The steps include the appropriate introduction of the topic, structured discussions covering potential scenarios, documentation of preferences, periodic review and update of the plans and directives, and application of the wishes when needed. The steps can then be flexibly integrated into routine clinical encounters by the physician and other members of the health care team. The process fosters personal resolution for the patient, preparedness for the proxy, and effective teamwork for the professionals. The process also has pitfalls to be aware of.

## Key words

Advance care planning, advance directive, advisory document, durable power of attorney for health care, honoring patient wishes, living will, personal preparation, pitfalls, proxy, statutory document, structured discussion, worksheet

## Objectives

The objectives of this module are to:

- Define advance care planning and explain its importance.
- Describe the steps of the advance care planning process.
- Describe the role of patient, proxy, physician, and others.
- Distinguish between statutory and advisory documents.
- Identify pitfalls and limitations in advance care planning.
- Be able to utilize planning to help the patient put affairs in order.

## Clinical case on trigger tape

A.G. is a 43-year-old woman diagnosed three years ago with breast cancer; she had 3 positive nodes and positive estrogen receptor status. She now has recurrent disease for a second time for which she is starting third line chemotherapy. She has young children and is finding it stressful to get through daily life; she is frightened by the thought of death.

### What is advance care planning?

Advance care planning is a process, not an event.<sup>1</sup> It is the *process of planning for future medical care in the event that the patient is unable to make his or her own decisions*. During this process patients explore, discuss, articulate, and document their preferences. The process helps patients identify and clarify their personal values and goals about health and medical treatment. They identify the care they would like, or not like, to receive in various situations. Patients also determine whom they would like to make health care decisions on their behalf in the event they cannot make decisions for themselves.

Ideally, advance care planning is a process of structured discussion and documentation woven into the regular process of care that is reviewed and updated on a regular basis.<sup>2</sup> It is designed to ensure that a patient's wishes will be respected in the event that the patient is unable to participate in decision-making. In the case of a pediatric patient, it is designed to ensure that the patient's parents are provided with an understandable discussion of the child's prognosis, and of the treatment options, should the child's condition deteriorate to a terminal state. The sense of control and peace of mind that this process fosters in the patient and the reduction in anxiety of proxy decision makers are important benefits.

Advance care planning is important for physicians for many reasons. Patients have a right to participate in the planning of their health care. Physicians have a legal and professional responsibility to assure this, even if the patient loses the capacity to make decisions. The process of determining those preferences for treatment builds trust and a sense of teamwork between the patient, the proxy, and the physician in several ways. The invitation to discuss future care permits the patient (or the parents if the patient is a child) to understand his or her own values, goals, and preferences that govern his or her life. The physician and proxy learn about those preferences and needs. The process helps to relieve anxieties and fears on both sides because a spirit of frankness and openness is fostered. Advance care planning is preventive medicine because it avoids future confusion and conflict.

The model for advance care planning can be applied to other decision-making processes as patients plan for the end of their lives (e.g., planning for bequests, autopsy, burial/cremation, funeral/memorial services, guardianship, choices of caregivers, and settings for care).

### Involvement of others

The physician plays an important role in initiating and guiding advance care planning. He or she needs to be involved in some, but not all, stages of advance care planning in order to understand the patient and establish a trustworthy, shared decision-making process.

Recent studies suggest that patients prefer discussing these issues with their family members.<sup>3</sup> However, as the physician will be responsible for the actual medical orders, sufficient involvement is necessary for the physician to feel comfortable that he or she can pursue the goals and priorities for care that the patient wants.<sup>4</sup>

Many physicians are concerned that advance care planning is too idealistic or time-intensive to include it in their busy practice. The purpose of this module is to provide a framework for the routine and practical inclusion of the process into practice. The patient, proxy, and family can do most of the work without the physician if they are given a worksheet and background materials. For purposes of reimbursement, the time that the physician takes to counsel and provide information about advance care planning can be incorporated into the coding of complexity of the encounter. Please refer to the section entitled “Reimbursement mechanisms and procedure/diagnosis coding for physician services in palliative care” in the Appendix of the EPEC materials.

Some physicians choose to have other members of the health care team assist them with advance care planning (e.g., a nurse, physician assistant or social worker).<sup>5</sup> Once the patient’s ideas have been gathered, the physician can focus on the core discussions in direct meetings with the patient, proxy, and family. Preparatory work will help these discussions that are to-the-point and effective. Once the core discussion has taken place, invite the patient to reflect on things and then return at a subsequent visit with decisions to review.

There are legitimate cultural, ethnic, and age related differences in approaches to medical decision making and advance care planning. However, generalizations should not be used to rationalize the omission of this topic for an individual patient. Pediatric patients and their parents can benefit from the advance care planning process.<sup>6</sup> Determine how a patient and family want medical information to be shared and medical decision making handled early in the therapeutic relationship. See EPEC-O Module 7: Communicating Effectively for a discussion of how to do this.

## **Definitions**

Terms used in advance care planning can be confusing. Advance directives are *prior directives from the patient for his or her health care*. Advance directives fall into two categories, those that have to do with instructions for medical care and those that have to do with designating a proxy for the patient. Instructional directives for care can be recorded in a number of types of documents. A living will is usually *a simple statement asking for no heroic care in case of poor prognosis*. A personal letter may also be used. A values history is *a statement of values regarding health care in life-threatening illness situations*. A medical directive is *a set of instructions based on likely scenarios of illness, goals for care, and specific treatments, combined with a general values statement*. It is also combined with a proxy designation section. *A person who is empowered to make decisions in the place of the patient* is sometimes termed a health care proxy or a durable power of attorney for health care. Laws and policies regarding advance care planning are

summarized in the Appendix of this module and are presented in more detail in the original *EPEC Curriculum's* Plenary 2: Legal Issues in End-of-life Care.

## 5 steps for successful advance care planning

### Step 1: Introduce the topic

Research shows that most patients believe that it is the physician's responsibility to start advance care planning and will wait for the physician's initiative.<sup>7</sup> Advance care planning is most easily accomplished during stable health, since changes often require a period for adjustment before the patient will have stable goals again.<sup>8</sup>

Ideally, oncologists will find that patients referred for cancer care come with documentation of prior advance care planning discussions fostered by the primary care physician. If this is the case, and the patient is not actively adjusting to a change in health status, it may be possible to note the presence of an advance directive document, confirm with the patient that preferences stated in it are not in need of change. After this introduction and acknowledgement of the topic, it is possible to note that it is recommended to revisit these plans periodically as part of normal care and indicate roughly when you would advise doing so for this patient. Then, after the therapeutic alliance is well established it is usually comfortable enough to return to the topic to revisit and revise any items as necessary.

Often, however, patients have no prior advance care planning documents and have had no prior discussions on the topic. Since, in the face of life-threatening illness or other significant change in health status, advance care planning becomes even more necessary, the oncologist must judge when it is best to raise the topic. Try to find a time when there is as much stability and adjustment to the new illness circumstances as possible. If this is not possible, place more than usual emphasis on having others present whom the patient can rely on.

Sometimes the most difficult part of the advance care planning process is the introduction of the topic. Physicians often have a number of concerns that make them reluctant to do so. Some may be concerned that the subject of advance care planning will frighten the patient or send the 'wrong message.' Others may be uncertain about the most effective approach to use. In fact, most patients welcome the opportunity to discuss their preferences with their physician, and physicians who routinely engage in the process find it helpful and not too time-consuming. This question should only be when and how to raise the topic.

For pediatric patients, the discussion should take place with the parents with much the same timing as for adult patients. Parents have a particularly difficult time adjusting to their child's cancer and its consequences, so allow as much time and counseling support as possible. Discussions should occur, at a minimum, at the time of relapse of disease, or at the time of significant complications, before the child is in a state of crisis.

When introducing the topic, start by inquiring how familiar the patient is with advance care planning, even if you have touched on the topic at the first meeting (see above). For patients who already have advance directives, review the documents and amend them if appropriate. An advisory medical directive can be used to amend existing statutory documents. (See step 3.)

Before beginning the process, be prepared to explain the goals and the process that you recommend using. You may have literature that you would like the patient to read. If you are using a validated worksheet, give it to the patient to look over before the next discussion. Explain the roles of other family members, or a proxy. If appropriate, introduce other members of the health care team who will be involved in the process.

While most patients will welcome the opportunity to discuss these matters, be aware of the patient's comfort level during the introduction of the topic. If a patient (or parent if the patient is a child) does not seem comfortable talking with you, be supportive and provide information, but do not force the conversation. It may happen later when the patient is ready. You should, if possible, note the default decision-making process with the legal next of kin should the patient be too ill to participate directly. This allows a patient who is seriously discontent with the default arrangement to prioritize making different arrangements with advance care planning even if the topic is difficult. It also allows the physician to feel comfortable using the default process should the patient not object and advance care planning turns out to be impossible under the circumstances.

As patients frequently wish to minimize the decision-making burden for family, suggest that the patient involve family members, friends, and even members of the community to explore how to best manage potential burdens. Ask the patient to identify a possible proxy decision maker who might act on his or her behalf, to be involved in subsequent conversations. The best proxy decision maker is not always a family member or significant other. Sometimes the decisions are too difficult for people close to the patient, who may be overly influenced by their attachment or by burdens of care. Whether close or not so close, the proxy should be someone whom the patient trusts and who would be willing and able to represent the patient's wishes. Encourage the patient to bring that person, or persons, to the next meeting and book a time to follow-up.

## **Step 2: Engage in structured discussions**

A critical success factor for advance care planning is the ability to structure discussions with the patient that both convey the information patients need and elicit relevant preferences to determine their advance directives.<sup>9,10</sup> A script is provided at the end of this module in the Appendix that you may wish to use or modify. It may help you to think about ways to conduct the discussion.

To prevent any misunderstanding, remind the patient that it is the goal of advance care planning to plan the potential loss of his or her capacity to make decisions, either temporarily or permanently. Convey the physician's and health care team's commitment to

follow the patient's wishes, desire to protect the patient from unwanted treatment or under-treatment, and desire to help plan for any caretaking needs of the patient's family or significant others.

## **Role of the proxy**

Involve the potential proxy decision maker in the discussions and planning so that he or she can have a thorough and explicit understanding of the patient's wishes. Usually, the appropriate role for the proxy during the initial discussions is to listen, perhaps to take notes, and to ask questions for clarification. A joint meeting between the patient, physician, and proxy to ensure common understanding can be invaluable if the proxy and physician are later called on to collaborate in decision-making.

As part of the advance care planning process, the patient should specify the role he or she would like the proxy to assume if the patient is incapacitated. Proxies may try to implement specific treatment choices, or they may try to decide according to the patient's best interests, or they may decide by taking into consideration the interests of all parties that the patient cares about in a form of substituted judgment. While these possibilities often coincide, they may not, and it can be very helpful for the patient to decide which standard is most important to him or her.

In all cases, the proxy will need to work with the physician and, in general, should have the same participation in decisions that the patient would have had. Most commonly, the proxy uses a blend of standards — his/her own best judgment based on the situation and what he/she knows about the patient's wishes. This allows for unexpected factors that could not be anticipated during the advance care planning process.

## **Patient and proxy education**

At the core of advance care planning is the empowerment and preparedness of the patient and proxy. Both usually require some education, time for reflection, and discussion. In order to make informed choices, the patient must understand the meaning of the various clinical scenarios under discussion, as well as the benefits and drawbacks of the various treatment options. The discussion should provide insight into the types of clinical scenarios that might arise and the types of decisions that proxies most commonly face.

Define key medical terms using words the patient and proxy can understand. Explain the benefits and burdens of various treatment options (eg, life support on a ventilator may only need to be used for a short time if the underlying problem is reversible). Remind them that any intervention can be refused or stopped if it is not meeting overall treatment goals (see EPEC-O Module 11: Withdrawing Nutrition, Hydration). Because recovery cannot always be predicted, help patients to consider situations involving uncertainty, incomplete recovery, or even death.<sup>11</sup>



## **Elicit the patient's values and goals**

Develop an understanding of the patient's values and goals related to health and illness (see EPEC-O Module 9: Negotiating Goals of Care). For pediatric patients, involve them to the level they are comfortable with and work with the parents/guardian. There are a number of ways to facilitate this part of the discussion. Ask about past experiences, either the patient's own or those of other people the patient knows. Describe possible scenarios and ask the patient what he or she would want in such a situation.

As a range of clinical situations is reviewed with the patient, it will be possible to get a sense of where thresholds exist for withdrawal or withholding of care. Help the patient to articulate his/her own general principles, values, and goals for care in given situations and specific treatment wishes. Consider asking the patient if he or she wants to write down in a letter to the physician how such things should be handled.

Some patients and proxies will have an emotional response to the material. Respond to the emotional reactions. Responding to emotions in the context of an interview is discussed in EPEC-O Module 7: Communicating Effectively.

## **Use a validated advisory document**

To guide the discussion and capture patient preferences, consider using a worksheet or other carefully developed and studied tool, such as a linear or interactive videotape or a software program. Many people find that, by using a worksheet, the discussion with the patient readily identifies the patient's values and attitudes regarding health and medical care across a range of medical situations, possible goals, and treatment choices. By going through various scenarios and options, the patient's personal threshold for use/nonuse of interventions can become clearer. Proxy decision makers can be identified and their roles defined.<sup>12, 13</sup>

Ensure that the worksheet includes a range of potential scenarios that patients should consider. It should elicit the patient's values and goals related to health and medical care in general terms and should include the most common life-saving interventions. If a patient already has a life-threatening condition, the conversation may be more focused on specific scenarios and treatment issues. For example, a patient with end-stage cardiomyopathy really needs to consider the issues of cardiopulmonary resuscitation (CPR) and the role of intensive care units. The patient with end-stage renal disease must consider dialysis. The patient with advanced AIDS needs to consider dementia and respiratory failure.

A number of validated worksheets are available to choose from (see the Appendix). They provide a consistent approach, are easy to use, and reduce the chance that important information will be left out or framed in a biased way; the preferences they elicit tend to be reliable and durable reflections of the patient's wishes. Once they are complete, worksheets can serve as a resource that the patient, proxy, and family members take home. They may also be able to serve as a formal advisory document.

## **Step 3: Document patient preferences**

### **Formalize the directives**

Once the patient has come to some decisions, it is crucial for the physician to review the advance directives with the patient and proxy. Check for, and help to correct, any inconsistencies and misunderstandings. Make sure that the directives provide the type of information needed to make clinical decisions.

After a final review is complete, ask the patient to confirm his or her wishes by signing the directives. Reassure the patient that the document can be changed as his or her wishes change. Although any statement of a patient's wishes, written or verbal, can be considered an advance directive and should be respected by physicians, a formal written document signed by the patient can avoid ambiguity.<sup>14, 15</sup>

### **Enter directives into the medical record**

Once the directives have been reviewed and accepted, document them in the patient's medical record. When a validated worksheet has been used to structure the planning discussion, the completed, finalized, and signed worksheet can itself be used as the entry in the medical record.

In the absence of a validated worksheet or document, the physician may describe the patient's wishes in a written document and ask the patient to review and amend it as appropriate. Once everyone is satisfied, have the patient sign the document and enter it into his or her medical record. It is also useful for the physician and proxy to sign the advance directive and provide their location information. This offers reassurance to the patient and helps to ensure the physician's and proxy's involvement in eventual decision making.<sup>16</sup>

### **Recommend statutory documents**

For added protection, patients should be encouraged to complete one or more statutory documents (e.g., living will or durable power of attorney for health care) that comply with state statutes. Physicians should familiarize themselves with the specific advance directive statutory requirements of their state. They can do this by checking with their hospital's legal counsel; their state attorney general's office, or their local medical society.

### **Distribute the directives**

It is important to have these records wherever the patient may receive care. Place them into a central repository (such as a hospital or a regional or national center). Provide copies to the patient, proxy decision maker, family members, and all health care provid-

ers as appropriate. Use wallet cards to help ensure that the information is available when it is needed.

## **Change the plan of care**

Once preferences have been documented, the physician may need to change the plan of care and put certain things in place to ensure that the patient's wishes can be followed. For patients who may wish to remain at home and never be taken to an emergency department or be hospitalized again, appropriate alternative arrangements, including referral to a home hospice agency, provision of appropriate medications, and instructions detailing how to handle symptoms and crises may possibly be needed. Practical suggestions may be helpful. Consider posting telephone numbers by the home telephone to call in an emergency (eg, the hospice nurse on call), or numbers not to call (eg, 911).

## **Step 4: Review and update the directive**

It is important to revisit the subject of advance care planning on a periodic basis to review the patient's preferences and update the documents. Major life events such as illness, marriage, the birth of a child, or the death of a loved one may affect a person's attitude toward their health care and/or end-of-life care.

Any changes in preferences warrant discussion to allow the patient to reassess and to ensure that the physician and proxy decision maker fully understand the new wishes.

Changes in preferences should be documented and existing documents should be updated and shared appropriately.

## **Step 5: Apply directives to actual circumstances**

When patients become incapacitated, the application of prior wishes to real circumstances can be challenging. The following guidelines may be helpful to ensure that a patient's advance directives are followed as closely as possible.

Most advance directives go into effect when the patient is no longer able to direct his or her own medical care. Learn to recognize when a patient becomes incapable of making decisions. While situations where the patient is unresponsive are obvious, if the patient has some ability to respond, the physician must first determine his or her capacity to make decisions (see EPEC-O Module 9: Negotiating Goals of Care).

Never assume an advance directive's content without actually reading the document. Do not take for granted that patients who have living wills want treatment withheld. Some people indicate within their living will that they want all full measures taken to prolong their life.

Advance directives should be interpreted in view of the clinical facts of the case. Validated documents are likely to be more useful than short statements or statutory documents. No matter how thorough they are, advance directives cannot anticipate all

possible circumstances. The proxy and the physician may need to extrapolate from the scenarios described in the advance directive to the current situation, and make an educated guess as to what the patient would want if he or she were able to speak for himself or herself.

Whenever significant interpretation is necessary, the physician should consult the patient's proxy. Sometimes the physician and/or proxy may believe that a patient would have indeed wanted something other than what is reflected by a strict reading of the advance directive. In this case, they should work together to reach consensus.

Certain patterns of decisions have high predictability and follow logically. For instance, a declination of less invasive interventions has been shown to predict declinations of more invasive interventions. Acceptance of more invasive interventions predicts acceptance of less invasive interventions. If a patient has indicated that he or she would like intervention in a poor-prognosis scenario, there is a high probability that the patient would also accept intervention in a better-prognosis situation. Likewise, if the patient has indicated he or she would decline intervention in a better-prognosis scenario, there is a high probability he or she would also decline if the prognosis were poor.<sup>17,18,19,20</sup>

If disagreements cannot be resolved, assistance should be sought from an ethics consultant or committee.

## Common pitfalls of advance care planning

Anticipating and avoiding the common pitfalls is essential to a successful advance care planning process. There are several:

**Failure to plan:** Do not avoid advance care planning. Too often, situations occur and decisions are made without the benefit of advance care planning. Be proactive. It is easy to forget the central role of the patient, and easy to forget the importance of the proxy. Involve both early and often.<sup>21,22,23</sup>

**Proxy not present for discussions:** Do not leave the proxy decision maker(s) out of the initial discussions with the patient.<sup>24,25,26</sup>

**Unclear patient preferences:** Vague statements can be dangerously misleading. Be sure to clarify patient preferences if they do not seem clear to you or to the proxy. For instance, patients who make statements such as “I never want to be kept alive on a machine” should be asked to clarify whether their wishes would change if their condition were readily reversible, or if their prognosis were unclear.<sup>27,28,29</sup>

**Discussion focused too narrowly:** Avoid isolated do-not-resuscitate (DNR) discussions; they often create chaotic emotions and thoughts in patients who have to imagine imminent death to make the decision. A DNR discussion is usually an indication that other palliative goals and measures should be considered in the context of a range of scenarios.<sup>30,31,32,33</sup>

**Communicative patients are ignored:** Sometimes people assume that what a patient wants in the present is what he or she indicated for future possible scenarios. As long as the patient is competent, talk to him or her. An impaired patient may still be able to express wishes at some level. In such cases, both the advance directive and tangible evidence of the patient's current wishes should be taken into account.

**Always read advance directives:** Sometimes physicians assume that they know what is stated in an advance directive. This is a mistake. Advance directives can be for aggressive intervention, comfort care, or a wide range of specific views and must be read and understood.<sup>34,35,36</sup>

## Complementary application of the model for advance care planning

### Preparation for the last stages of life

Planning other issues that face patients at the end of their lives is critical if their needs and expectations are to be respected by health care professionals and family members who will survive them. While it would be ideal if all patients and families prepared for death well in advance of the final hours of their lives, most patients with advanced illnesses and their families have neither discussed nor prepared for their death.

As patients approach the last hours of their lives, they have a last chance to finish their business, create final memories, give final gifts, and say their good-byes. If appropriately assisted, considerable planning can be accomplished around many of these issues.

A refined sense of when the patient and family are ready to engage in this type of planning is needed, as well as a reasonable sense for the patient's prognosis and an ability to distinguish the patient and family needs from the professionals' feelings. Often patients and families are ready for these discussions before the professionals. Such discussions need not be left for the last possible stages; if conducted when patients have a good amount of time left, it can lead to a helpful sense of peace and order while they then get on with living life and seeking their care goals.

The 5-step model for eliciting, documenting, and following advance directives can be used to guide these decision-making processes and document patient choices. As these important tasks are generally more than individual physicians can handle, other members of the interdisciplinary team can help patients and families complete their business and get their affairs in order.

In preparing for death, it is important to understand the perspective and wishes of all who are present: the patient, the family, and the caregivers. Personal expectations, agendas, fears, phobias, and acceptable setting(s) for care need to be clear, since any one person may alter the course of care unexpectedly and may interfere with the patient's wishes if such are not clearly known. Personal, cultural, and religious values, beliefs, and practices need to be anticipated and respected, as missed rites/rituals or errors made by unknowing

caregivers may have grievous consequences in the eyes of the patient or family members. Identification and acknowledgment that some family members have a need to give care and others don't will help to allow each to participate as closely as makes him/her comfortable.

## **Advance practical planning**

Many patients will choose to get their financial and legal affairs in order, give gifts and plan for bequests, organ donation, autopsy, burial/cremation, their funeral/memorial services, and guardianship of their children as they finish their business. Some patients will even want to give family members permission to build new lives after they die.

## **Choice of caregivers**

The choice of caregivers for each patient is crucial as vulnerability increases. Early in an illness there is still time to discuss and plan for the best configuration. Patients may or may not want family members to care for them. Family members may or may not be able to assume responsibilities for caring and should ideally have the opportunity to be family first and caregivers only if both they and the patient agree to the role. All caregivers need to have the opportunity to change their role if they feel the stress is too much, or they are not getting enough chance to finish their personal business with the patient.

## **Choice of setting**

The choice of the care setting for the last hours of a person's life should be as acceptable as possible to the patient, the family, and all caregivers. Each setting will carry benefits and burdens. Whatever the choice, the setting should permit family members to remain with the patient as much as they want, and provide them with opportunities for privacy and intimacy. While dying at home may be the wish of many patients, such a choice may expose family members to undue burden or compromise their careers, their personal economic resources, or their health. If the number of able caregivers and personal resources is limited or if family members are afraid of ghosts and would not be able to live on in their home afterward, care and death in the home may not be the best choice. An alternate inpatient setting may be a hospice or palliative care facility, a skilled nursing facility, or even an acute care facility. Depending on the resources that are locally available and whether the staff is skilled in this kind of care, these alternative settings may lead to a far better outcome.

## **Summary**

Advance care planning should be a routine part of standard medical care that is integrated into clinical encounters by the physician and other members of the health care team. Formally, it can be thought of as a stepwise approach, to include the appropriate introduction of the topic, structured discussions covering potential scenarios, documentation

of preferences, periodic review and update of the directives, and application of the patient's wishes when needed. Less formally, the process fosters personal resolution for the patient, preparedness for the proxy, and effective teamwork for the professionals.

A number of critical factors contribute to a successful process and outcome: physician guidance and participation, family/proxy participation, and use of a worksheet or structured materials to foster discussion and documentation.

The process also has pitfalls to be aware of. Vague or misleading statements of wishes can be hazardous; failure to involve the proxy risks discord around decisions; premature activation of the directive when the patient is still competent fails to honor the patient's real-time autonomy; and assumptions about wishes in advance directives being for non-intervention may not be accurate.

## Resources

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## Appendix

### Advance care planning: The law and policy

Common law, federal and state legislation, and official policies of medical organizations support advance care planning.

- **US Supreme Court, 1990:** Upheld the patient's right to self-determination, establishing that the right applies even to patients who are no longer able to direct their own health care, and that decisions for incompetent patients should be based on their previously stated wishes.
- **Federal law, 1991:** The Patient Self-determination Act requires that patients be informed of their rights to accept or refuse medical treatment and to specify in advance the care they would like to receive should they become incapacitated.
- **State law:** The patient's right to specify wishes in advance has been codified into statute in all 50 states. Statutory documents recognized by law include the living will and the durable power of attorney for health care.
- **Statutory documents** are those that are specifically described and defined in state statute. These documents are to help protect physicians who honor a patient's wishes. When such documents are used, rights, obligations, and protections are clearly defined. Nonstatutory documents or advisory documents are legal. They are based on common law rights. They are supposed to accurately reflect a patient's wishes. In some states or settings, an advisory document is enough; in others, a statutory form should be used as well. Especially in states where a legal guardian may be necessary if there is no statutory power of attorney for health care, one is recommended.
- **Professional policy:** The AMA's Council on Ethical and Judicial Affairs identified advance care planning as an essential component of standard medical care in 1997. It called for physicians to conduct advance care planning discussions on a routine basis using advisory documents as an adjunct to statutory documents, such as the living will and the durable power of attorney for health care. The American College of Physicians' *Ethics Manual*, 4th edition, 1998, also supports advance care planning.



## Advance care planning discussion scripts

Mrs. Jones has come in for a routine examination:

“Mrs. Jones, I’d like to talk with you about something I try to discuss with all of my patients. It’s called advance care planning. In fact, I feel that this is such an important topic that I have done this myself, with my own physician. Are you familiar with advance care planning?...”

“Have you thought about the type of medical care you would like to have if you ever became too sick to speak for yourself? That is the purpose of advance care planning, to ensure that you are cared for the way you would want to be, even in times when communication may be impossible....”

“There is no change in your health that we have not already discussed. I am bringing this up now because it is prudent for everyone, no matter what their age or state of health, to plan for the future....”

“Advance care planning will help both of us to understand your values and goals for health care if you were to become critically ill. Eventually we may put your choices into a written document that I would make part of your patient record. We call this document an advance directive, and it would only be used if you were to lose the capacity to make decisions on your own, either temporarily or permanently....”

“Would you like to talk further about the kind of care you would want to have if you were no longer able to express your own wishes?”

“I also like to ask my patients if they have someone that they would like to identify to act on their behalf in the event that they are unable to express their own wishes. This person could be a relative or a friend. Is there someone whom you would want to be part of our discussion and whom you might want to have act on your behalf?...”

“Here is a copy of the form that I would like to use to structure our conversation. We will talk about it in more depth the next time we meet. Please think about it, talk with your family, and write down any questions you have. Also, next time please bring anyone with you whom you want to include in our discussion....”

### **Next visit:**

Ask questions about specific scenarios. Start by asking about a persistent vegetative state.

“Mrs. Jones, I suggest we start by considering a few examples as a way of getting to know your thinking. I will use examples that I use for everyone. Let’s try to imagine several circumstances. First, imagine you were in a coma with no awareness. Assume there was a slight chance that you might wake up and be yourself again, but it was not likely. Some people would want us to withdraw treatment and let them die, others would want us to attempt everything possible, and yet others would want us to try to restore

health, but stop treatment and allow death if it were not working. What do you think you would want under these circumstances?”

Then ask Mrs. Jones similar questions about 3 other scenarios:

- Onset of coma from which there is a chance of recovery, but with significant disability.
- Onset of dementia when there is already an advanced life-threatening illness.

If she is already experiencing a significant illness, ask Mrs. Jones questions specific to her current illness:

“We should also consider the situations that your particular illness can cause; that way you can be confident we will do what you want. For sure, all people are different and you may never face these circumstances. Nevertheless, let’s imagine . . .”

“People sometimes think about circumstances they have seen or heard about. Some may seem worse than death. Do you ever think about such circumstances?”

Finally, ask Mrs. Jones about how she would like to handle a sudden critical illness were it to happen with her current health that were to be life threatening.

At the end of these scenarios, recap what you understand:

“Well, we’ve gone through several scenarios now. It seems to me that you feel particularly strongly about.... Indeed, you move from wanting intervention to wanting to be allowed to die in peace at the point when.... Do I speak for you correctly if I say that your personal threshold for deciding to let go is ...?”

Conclude by inquiring about broader values and beliefs:

“I think you have given a good picture of particular decisions you would want. Can you also say something about the values or beliefs that you hold? Understanding your more general views can be an important part of getting specific decisions right.”

**Next visit:**

“Mrs. Jones, have you and [your proxy/family member] had a chance to continue the discussion we started 2 weeks ago? I see you have a completed statement now. Let’s review your preferences.”

“I am glad we went through this planning process together. I have a much better idea of what matters to you than I did before, and that will help me to be a good physician for you — in general, as well as in case of serious illness.”

“If you feel ready to, we can write down your preferences, and all 3 of us can sign this document and make it official. Then we will put it into your medical record and give you copies to take home.”

**After a change in health status (such as relapse), after allowing time to adjust to the new reality:**

“Mrs. Jones, we have had some changes in your health since we completed your advance care plans. People sometimes change their wishes, so let’s review the wishes you wrote down before.”

**If the patient seems unsure of decisions:**

“Your choices have changed on a couple of your earlier decisions when we reviewed your statement. You have also said that you want [proxy/family member] to be your proxy. Would you prefer to give these few decisions over to him/her to decide according to what he/she thinks would be in your best interests?”

“For the remaining decisions, about which you are clear and firm, would you like [proxy/family member] to stick closely to them, or would you prefer to give him/her room to make changes if he/she thinks your best interests would be better served by a different decision?”

## **Advance care planning exercise**

*This is an exercise to help **physicians, and other health providers**, learn about advance care planning. It is written essentially as a script for a facilitated group process. The educational method is interactive rather than didactic. The scenarios are designed for people in generally good health and would not be duplicated exactly for cancer patients. Rather, this exercise allows health care professionals to get used to advance care planning for themselves as a step in the process of being competent to assist patients in their process.*

It is helpful to be able to say to patients and families that you have done your own advance care planning as a matter of routine care. It is also helpful to have experienced the process of trying to imagine being in states of serious illness and mental incapacity.

### **First scenario**

We will start by considering a scenario in which you have an advanced illness with a very poor prognosis (less than 3 months if the disease follows its usual course). You are in the hospital in a coma with a poor likelihood of recovery when you develop a small bowel obstruction.

First, consider what you would want to be the *goals* of your care in this circumstance. Would you want (a) all possible intervention to prolong life, (b) full intervention, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want major surgery? [*Pause briefly.*] How about an intermediate option with a nasogastric tube, and no intake by

mouth? [*Pause briefly.*] How about only intravenous antibiotics? [*Pause briefly.*] What about only comfort measures with analgesics and sedatives?

Let's look at what goals you selected. How many of you selected all possible interventions to prolong life? [*You may want to list this on the left-hand side of a flip chart or overhead projector. Count hands and record the number.*] How many selected full interventions, but with early reassessment? [*Count hands and record the number.*] How many chose interventions that might help but are not too invasive? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Let's look at what treatment options you selected. How many wanted major surgery? [*Count hands and record the number on the right-hand side of the flip chart or overhead projector opposite the corresponding goal.*] How many wanted intermediate interventions with an NG tube? [*Count hands and record the number.*] How many wanted antibiotics? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Notice how many of you declined all interventions and wanted only comfort measures. Some of you wanted some noninvasive or minimally invasive measures. Also, notice the inconsistencies. When faced with specific choices, some of you changed to a different "level" as related to overall goals. If we were to move to a scenario of rosier prognosis, we would still be likely to find a range of choices within the group. Many of you would change your choices.

This process leads to an opportunity to think about your own internal inconsistencies, how you might value various options, and how you would set limits. Further, it helps you to be specific about your relationship to death and dying.

Many of the questions in your mind are questions that patients will have. Many are those that only people with advanced education ask. In fact, lawyers and physicians tend to be either the fastest or the slowest to complete these types of exercises. Most people, regardless of educational experience, find these exercises helpful and doable.

## **Second scenario**

Now, consider a scenario in which you have a mild chronic condition. It affects your day-to-day living to a modest degree. You now contract a life-threatening but potentially reversible condition such as *Staphylococcus aureus* pneumonia. You are barely conscious and cannot make decisions for yourself. Let's go through the same exercise. First, let's discuss goals. Would you want (a) all possible intervention to prolong life, (b) intervention, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want care in an intensive care unit, including pressors and intubation? [*Pause briefly.*] Would you want a more

intermediate intervention, such as multiple intravenous antibiotics and low-dose pressors but no transfer to an intensive care unit and no intubation? [*Pause briefly.*]

Now consider a barely invasive intervention — would you want IV antibiotics but a limit on the degree of laboratory testing? [*Pause briefly.*] Would you want only comfort care with analgesics and sedatives? [*Pause briefly.*]

Let's look at what you selected now. How many of you selected all possible interventions to prolong life? [*You may want to list this on a flip chart or overhead projector on the left hand side, as before. Count hands and record the number.*] How many selected intervention, but with early reassessment? [*Count hands and record the number.*] How many chose interventions that might help but not too invasive? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Let's look at what treatment options you selected. How many chose all measures to prolong life? [*Count hands and record the number on the right-hand side of the flip chart or overhead projector opposite the corresponding goal.*] How many wanted intermediate interventions with IV antibiotics, but no ICU care? [*Count hands and record the number.*] How many wanted only IV antibiotics? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Notice the changes. Most of you wanted interventions that were much more “aggressive.” Contrast your answers to this scenario with the first. Do you have a sense of where your threshold for intervention lies relative to prognosis and disability? Some of you could now move to other scenarios and treatments that would more clearly define your personal threshold for intervention. For many people, it is enough to define where the threshold is, without resolved detailed decisions at the threshold. Often this is where physician recommendation plays a stronger role and proxy discretion comes in. Many patients are content with this.

Notice how most of you selected intervention choices that were consistent with your general goal. This is usually the case. However, some of you chose treatments that didn't quite correspond with the overall goal. Research shows that trying to predict intervention choices from stated general goals (such as those in a living will) is weaker than extrapolating from specific preferences. While identifying goals provides a reality check and organizes our thinking, this is not a substitute for considering specific examples.

Most people, after weighing other scenarios and having fully completed an advance care planning worksheet, will feel that their views are well articulated. Some proportion of patients, however, will feel that there is something more that needs to be said. Invite them to give you a statement in their own words, such as in a letter. Ask them to consider other matters, such as whether the patient wants to die at home, or whether autopsy and/or organ donation is desired. Invite the formal proxy to be designated. If more than one proxy is desired, invite the patient to give some sense of order of authority in cases of disagreement.

## Appendix: reprinted documents

The Medical Directive, reprinted by permission of Linda L. Emanuel, Ezekiel J. Emanuel, and the American Medical Association.

Thought-provoking exercises, from a research workbook entitled “*Your Life, Your Choices.*” Reprinted by permission. An updated version, “*If I Can’t Speak For Myself...*” Copyright 1999, published by Patient Decision Support. ([www.patientdecision.com](http://www.patientdecision.com).)

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## References

<sup>1</sup> Westley C, Briggs LA. Using the stages of change model to improve communication about advance care planning. *Nurs Forum*. 2004;39(3):5-12. Review. [PMID: 15551794](#).

Incorporating behavioral change theory helps develop workable interventions and provides strategies for nurses to approach patients appropriately about planning for future medical care.

<sup>2</sup> Weissman DE. Decision making at a time of crisis near the end of life. *JAMA*. 2004;292(14):1738-1743. [PMID: 15479939](#). [Full text](#)

Key factors in the decision process include prognosis, risk-benefit analysis of the proposed intervention, current symptom burden, temporal pattern of the illness, patient's age and life stage, and the patient's goals of care. A structured approach to decision making includes assessing the patient's physical, psychological, and spiritual needs; assessing the patient's support system; discussing prognosis; and assessing patient-specific goals. Physicians can best help patients decide which treatments are appropriate by taking the necessary time to explore all curative and palliative care options, providing honest and timely prognostic information, making clear recommendations, facilitating patient-family discussions, and affirming patient choices.

<sup>3</sup> Karel MJ, Powell J, Cantor MD. Using a Values Discussion Guide to facilitate communication in advance care planning. *Patient Educ Couns*. 2004;55(1):22-31. [PMID: 15476986](#). [Full text](#)

A Values Discussion Guide (VDG) was administered to 10 male Veterans Health Administration outpatients over age 50 and their health care agents. Most participants found the VDG to be helpful and reassuring. Discussions varied in quantity and quality, and participants varied in preferring self-guided versus professionally facilitated discussions. The best interchanges were elicited by questions about prior experience with medical decisions, for oneself or others, and trusted versus non-trusted others to help with decision-making.

- <sup>4</sup> Bern-Klug M, Gessert CE, Crenner CW, Buenaver M, Skirchak D. "Getting everyone on the same page": nursing home physicians' perspectives on end-of-life care. *J Palliat Med.* 2004;7(4):533-544. [PMID: 15353097](#). [Full text](#)

Interviews of 12 nursing home physicians, yielded four themes: extensive familiarity with dying; consensus is integral to good end-of-life care; obstacles can interfere with consensus; and advance directives set the stage for conversations about end-of-life care.

- <sup>5</sup> Henderson ML. Gerontological advance practice nurses: as end-of-life care facilitators. *Geriatr Nurs.* 2004;25(4):233-237. [PMID: 15311200](#). [Full text](#)

This article proposes a model in which the Gerontological advance practice nurses offers 5 essential services in caring for the patient and family based on their needs and on the principles of end-of-life (EOL) care: 1) assessment of the living situation; 2) symptom management and enhancement of quality of life; 3) advance care planning (ACP); 4) patient and family counseling (emotional, social, spiritual); and 5) continuity, communication, and coordination of care.

- <sup>6</sup> Wharton RH, Levine K, Buka S, Sheinberg N, Emanuel LL. Advance care planning for children with special health care needs: a survey of parental attitudes. *Pediatrics* 1996;97:682-687.

This paper explores how clinicians, parents and children of various ages with health care needs can collaborate in making advance care planning part of the care process.

- <sup>7</sup> Lo B, Steinbrook R. Resuscitating advance directives. *Arch Intern Med.* 2004;164(14):1501-1506. [PMID: 15277279](#). [Full text](#)

Advance directives would be more useful if they emphasized discussing end-of-life care with physicians rather than completing a legal document. Procedures for written advance directives should be simplified.

- <sup>8</sup> Laakkonen ML, Pitkala KH, Strandberg TE, Berglund S, Tilvis RS. Living will, resuscitation preferences, and attitudes towards life in an aged population. *Gerontology.* 2004;50(4):247-254. [PMID: 15258431](#). [Full text](#)

378 home-dwelling elderly individuals were asked about a preexistence of a written document (LW) Forty-four of the 378 participants (12%) had a LW. Despite having a LW, 46% (20/44) of them preferred CPR in their current condition, a proportion not statistically different from the 58% (194/334) of the individuals without a LW. In the whole sample, 39% (149/378) of the individuals preferred to forgo CPR.

- <sup>9</sup> Kessler DP, McClellan MB. Advance directives and medical treatment at the end of life. *J Health Econ.* 2004;23(1):111-127. [PMID: 15154690](#). [Full text](#)

Analyzed the medical care of elderly Medicare beneficiaries who died between 1985 and 1995. Three key findings: 1) laws enhancing incentives for compliance significantly reduce the probability of dying in an acute care hospital; 2) laws requiring the appointment of a surrogate significantly increase the probability of receiving acute care in the last month of life, but decrease the probability of receiving nonacute care; 3) neither type of law leads to any savings in medical expenditures.

- <sup>10</sup> Kass-Bartelmes BL, Hughes R. Advance care planning: preferences for care at the end of life. *J Pain Palliat Care Pharmacother.* 2004;18(1):87-109. Review. [PMID: 15148012](#).

Most patients have not participated in advance care planning and the need for more effective planning is documented. Results of patient responses to hypothetical scenarios are described.

- <sup>11</sup> Quill TE. Dying and decision making--evolution of end-of-life options. *N Engl J Med.* 2004;350(20):2029-2032. [PMID: 15141040](#). [Full text](#)

- <sup>12</sup> Schwartz CE, Merriman MP, Reed GW, Hammes BJ. Measuring patient treatment preferences in end-of-life care research: applications for advance care planning interventions and response shift research. *J Palliat Med.* 2004;7(2):233-245. [PMID: 15130201](#). [Full text](#)

Seriously ill patients (n = 168) were asked at baseline and 21 days to consider four common end-of-life health state scenarios, to indicate their goals for treatment, and to state their preferences for six specific treatments. Preferences for life-sustaining treatments were highly intercorrelated, and internally consistent across treatments by scenario and across scenarios by treatment. Preferences for pain medications were, however, distinct from preferences for other treatments. Preference scores exhibited stability over follow-up, and demonstrated both concurrent and discriminant validity. We detected a small effect size for change in preferences as a function of health state change, suggesting that re-prioritization response shifts do occur but are small in magnitude in these patient samples over this time frame.

- <sup>13</sup> Bialk JL. Ethical guidelines for assisting patients with end-of-life decision making. *Medsurg Nurs.* 2004;13(2):87-90. [PMID: 15119420](#).

By using a decision framework, the nurse will be better prepared to assist patients in exploring options for end-of-life care.

- <sup>14</sup> Matulonis UA. End of life issues in older patients. *Semin Oncol.* 2004;31(2):274-281. Review. [PMID: 15112156](#).

The elderly with cancer at the end of their life are more at risk for untreated pain and depression and are more likely to commit suicide than their younger counter parts.

- <sup>15</sup> Patel RV, Sinuff T, Cook DJ. Influencing advance directive completion rates in non-terminally ill patients: a systematic review. *J Crit Care.* 2004;19(1):1-9. Review. [PMID: 15100999](#). [Full text](#)

Nine Randomized Controlled Trials were evaluated (N=3,206). Overall, methodologic quality and reporting transparency were poor. Trials with greater methodologic rigor and reporting transparency produced a more conservative estimate of effect, 2.42 [0.96, 6.10] versus 28.69 [5.08, 162.06] for less rigorous and poorly reported trials (P =.013). Advance directive completion rates documenting patient preferences for end-of-life care may be increased by simple patient-directed educational interventions.

- <sup>16</sup> Seymour J, Gott M, Bellamy G, Ahmedzai SH, Clark D. Planning for the end of life: the views of older people about advance care statements. *Soc Sci Med.* 2004;59(1):57-68. [PMID: 15087143](#). [Full text](#)

Focus groups explored views of 32 older people or their representatives who belonged to six diverse community groups in Sheffield, UK. Advance statements were understood primarily in terms of their potential to aid personal integrity and to help the families of older people by reducing the perceived 'burden' of their decision making. However, concerns were expressed about the perceived link between advance care statements and euthanasia, their future applicability, and the possibility that preferences for care may change. Participants also reported worries and difficulties related to thinking about and discussing death and dying. Trust between doctor and patient, built up over time, was perceived to be important in creating an environment in which the communication necessary to underpin advance care planning could take place. Lastly, participants did not perceive that during dying they would be ready necessarily to adhere to an advance statement and 'disengage' from their lives.

- <sup>17</sup> Tilden VP, Tolle SW, Drach LL, Perrin NA. Out-of-hospital death: advance care planning, decedent symptoms, and caregiver burden. *J Am Geriatr Soc.* 2004;52(4):532-539. [PMID: 15066067](#). [Full text](#)

A 69-item telephone questionnaire with single-item indicators and embedded scales that indexed advance directives, use of life-sustaining treatments, hospice enrollment, decedent symptom experience and perceived distress, family financial hardship, out-of-pocket expenses, and caregiver strain was



administered to 1189 family caregivers of decedents aged 65 and older who died of natural deaths in community settings between 2000 and 2002. Most decedents had advance directives (78.3%) and were enrolled in hospice (62.4%). Despite high rates of advance directives and hospice enrollment, perceived symptom distress was high for a subset of decedents, and caregiver strain was common.

- <sup>18</sup> Pekmezaris R, Breuer L, Zaballero A, Wolf-Klein G, Jadoon E, D'Olimpio JT, Guzik H, Foley CJ, Weiner J, Chan S. Predictors of site of death of end-of-life patients: the importance of specificity in advance directives. *J Palliat Med.* 2004;7(1):9-17. [PMID: 15000779](#). [Full text](#)

The medical records of 100 deceased consecutive nursing home residents, stratified by site of death (skilled nursing facility or acute care hospital), were reviewed. Significantly higher proportions of patients dying in the nursing home had specific advance directives (do not resuscitate, do not intubate, do not artificially feed, do not hydrate, and do not hospitalize), as opposed to those dying in the hospital.

- <sup>19</sup> Perkins HS, Cortez JD, Hazuda HP. Advance care planning: does patient gender make a difference? *Am J Med Sci.* 2004;327(1):25-32. [PMID: 14722393](#). [Full text](#)

26 Mexican American (14 male, 12 female), 18 European American (7 male, 11 female), and 14 African American (7 male, 7 female) inpatients were asked about their attitudes about advance care planning and dying. The interviews identified 40 themes. Five, including "Advance directives (ADs) improve the chances a patient's wishes will be followed," No individual themes distinguished the genders across ethnic groups. However, 3 meta-themes--or clusters of related themes--did. Men's end-of-life wishes addressed functional outcome alone, but women's wishes addressed other factors, too. Men felt disempowered by the health system, but women felt empowered. Men feared harm from the system, but women anticipated benefit. Each ethnic group expressed these gender differences uniquely.

- <sup>20</sup> Abraham JL. Waiting for the platelet count to rise: negotiating care at the end of life. *Cancer Invest.* 2003;21(5):772-781. Review. [PMID: 14628435](#).

Using language that displays their concern for providing ongoing care and that does not mistakenly imply withholding of effective therapies can ease the transition off chemotherapy. Providing accurate, timely prognostic information; exploring patients' hopes, goals, and values; helping them resume meaningful activities; meeting their health care proxies and discussing the advance care plan with them can all enhance the relationship with patients at the end of life and ease fears of abandonment.

- <sup>21</sup> Phipps EJ, True G, Murray GF. Community perspectives on advance care planning: report from the Community Ethics Program. *J Cult Divers.* 2003;10(4):118-123. Review. [PMID: 15000054](#).

Community forums and focus groups were held with African-American, Korean-American, and Latino communities in Philadelphia between 2000 and 2001. Concerns related to end of life and advance care planning were specific to each community, as well as themes that cut across communities.

- <sup>22</sup> Berger JT. Ethical challenges of partial do-not-resuscitate (DNR) orders: placing DNR orders in the context of a life-threatening conditions care plan. *Arch Intern Med.* 2003;163(19):2270-2275. [PMID: 14581244](#). [Full text](#)

Do-not-resuscitate (DNR) orders are commonly found in treatment plans for patients near the end of life. Orders for partial resuscitation (eg, "do not intubate") have evolved from DNR orders. Although the ethics of DNR orders have been widely examined in the medical literature, little has been written about the ethics of partial resuscitation. This article explores the ethical implications of partial DNR orders and identifies the need to develop care plans addressing life-threatening conditions for patients with DNR orders.

- <sup>23</sup> Bricker LJ, Lambing A, Markey C. Enhancing communication for end-of-life care: an electronic advance directive process. *J Palliat Med.* 2003;6(3):511-519. [PMID: 14509500](#). [Full text](#)

This paper describes the development of an electronic advance directive to facilitate access to a patient's treatment wishes at any site in our health care system. The successes and challenges encountered in the development process are discussed.

- <sup>24</sup> Doukas DJ, Hardwig J. Using the family covenant in planning end-of-life care: obligations and promises of patients, families, and physicians. *J Am Geriatr Soc.* 2003;51(8):1155-1158. [PMID: 12890082](#). [Full text](#)

The current use of advance directives fails to respect patient autonomy. The family covenant formulates advance directives in conversation with family members and with the assistance of a physician, thereby making advance directives more acceptable to the family and more intelligible to other physicians. These negotiations between patient, family, and physician, from early planning phases through implementation, should greatly reduce the incidence of family disagreements on what the patient would have wanted.

- <sup>25</sup> Fried TR, Bradley EH. What matters to seriously ill older persons making end-of-life treatment decisions?: A qualitative study. *J Palliat Med.* 2003;6(2):237-244. [PMID: 12854940](#). [Full text](#)

23 patients, 60 years of age and older with a primary diagnosis of congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), or cancer identified by their physicians as having a limited life expectancy took part in in-depth semistructured interviews and focus groups in which they were asked to discuss how they had made previous decisions about the treatment of their illness and/or would think about making future decisions. There were three major influences on treatment preferences: treatment burden, treatment outcome, and the likelihood of the outcome.

- <sup>26</sup> Allen RS, DeLaine SR, Chaplin WF, Marson DC, Bourgeois MS, Dijkstra K, Burgio LD. Advance care planning in nursing homes: correlates of capacity and possession of advance directives. *Gerontologist.* 2003;43(3):309-317. [PMID: 12810894](#). [Full text](#)

78 nursing home residents (M age = 83.97, SD = 8.2) and their proxies (M age = 59.23, SD = 11.77) were included across five nursing homes. Capacity assessments revealed that most residents could state a simple treatment preference (82.4%), but a sizable number did not retain capacity to understand treatment alternatives or appreciate the consequences of their choice. Residents were more likely to possess advance directives when proxies possessed advance directives, proxies were less religious, and residents were socially engaged.

- <sup>27</sup> Cohen-Mansfield J, Libin A, Lipson S. Differences in presenting advance directives in the chart, in the minimum data set, and through the staff's perceptions. *Gerontologist.* 2003;43(3):302-308. [PMID: 12810893](#). [Full text](#)

122 elderly persons who reside in one large (587 beds) nursing home. The rates of documented advance directives found in this study are higher than those reported in the literature. However, agreement varied between 3 sources: Inside the chart, the cover of the chart, and the MDS.

- <sup>28</sup> Gallo JJ, Straton JB, Klag MJ, Meoni LA, Sulmasy DP, Wang NY, Ford DE. Life-sustaining treatments: what do physicians want and do they express their wishes to others? *J Am Geriatr Soc.* 2003;51(7):961-969. [PMID: 12834516](#). [Full text](#)

Of 999 physicians who were sent a questionnaire about advance directives, 765 (77%) responded. Forty-six percent of the physicians felt that their own doctors were unaware of their treatment preferences or were not sure, and of these respondents, 59% had no intention of discussing their wishes with their doctors within the next year. In contrast, 89% thought their families were probably or definitely aware of their preferences. Sixty-four percent reported that they had established an advance directive. Compared with physicians without advance directives, physicians who established an advance directive were more likely to believe that their doctors (odds ratio (OR) = 3.42, 95% confidence interval (CI) = 2.49-4.69) or

family members (OR = 9.58, 95% CI = 5.33-17.23) were aware of their preferences for end-of-life care and were more likely to refuse treatments than those without advance directives.

- <sup>29</sup> Pfeifer MP, Mitchell CK, Chamberlain L. The value of disease severity in predicting patient readiness to address end-of-life issues. *Arch Intern Med.* 2003;163(5):609-612. [PMID: 12622608](#). [Full text](#)

100 outpatients with a diagnosis of chronic lung disease presenting for pulmonary function testing were assessed. In multivariate analysis, patient desire for an end-of-life discussion with the physician was not associated with percentage of predicted forced expiratory volume in 1 second (odds ratio [OR], 0.99; 95% confidence interval [CI], 0.96-1.03), oral corticosteroid use (OR, 1.34; 95% CI, 0.40-4.54), functional status score (OR, 1.37; 95% CI, 0.34-5.56), hospitalizations in the past year (OR, 0.33; 95% CI, 0.09-1.20), or previous mechanical ventilation (OR, 1.37; 95% CI, 0.34-5.56).

- <sup>30</sup> Kolarik RC, Arnold RM, Fischer GS, Tulsy JA. Objectives for advance care planning. *J Palliat Med.* 2002;5(5):697-704. Review. [PMID: 12572968](#). [Full text](#)

The first step to improving outcomes in ACP is to acknowledge the diversity of objectives that ACP may achieve. Health care providers, patients, and surrogates should identify and agree on common objectives for particular conversations. Various methods, conversations, and forms may be used to achieve these objectives over time.

- <sup>31</sup> Kolarik RC, Arnold RM, Fischer GS, Hanusa BH. Advance care planning. *J Gen Intern Med.* 2002;17(8):618-624. [PMID: 12213143](#). [Full text](#)

Outpatients age 55 or older who did not have an AD and were not demented were randomly assigned to complete either Emanuel's Medical Directive (EMD) or Pearlman's values history (PVH) form. Of the 275 patients approached, 143 refused, 69 already had an AD, 63 patients were enrolled, and 25 in each group completed the telephone interview. Both the values-based and treatment-based AD forms were rated favorably overall. Patients thought the treatment-based directive would give them more control over their care. Patients completing the values history form were more likely to designate a surrogate. Patients are likely to discuss both types of AD with family, but neither form alone is likely to lead to AD conversations with physicians.

- <sup>32</sup> Happ MB, Capezuti E, Strumpf NE, Wagner L, Cunningham S, Evans L, Maislin G. Advance care planning and end-of-life care for hospitalized nursing home residents. *J Am Geriatr Soc.* 2002;50(5):829-835. [PMID: 12028168](#). [Full text](#)

Nursing home records and gerontological advanced practice nurse field notes from 43 deceased residents hospitalized within the last 6 weeks of life at a tertiary medical center were abstracted. Advance care planning was addressed by social workers as part of the nursing home admission process, focused primarily on cardiopulmonary resuscitation preference, and reviewed only after the crisis of acute illness and hospitalization. Advance directive forms specifying preferences or limitations for life-sustaining treatment contained inconsistent language and vague conditions for implementation. ACP review generally resulted in gradual limitation of life-sustaining treatment. Transition points included nursing home admission, acute illness or hospitalization, and decline toward death. Relatively few nursing home residents received hospice services, with most hospice referrals and palliative care treatment delayed until the week before death. Most residents in this sample died without family present and with little documented evidence of pain or symptom management.

- <sup>33</sup> Hines SC, Glover JJ, Babrow AS, Holley JL, Badzek LA, Moss AH. Improving advance care planning by accommodating family preferences. *J Palliat Med.* 2001;4(4):481-489. [PMID: 11798480](#). [Full text](#)

242 pairs of dialysis patients and their designated surrogates were interviewed. Ninety percent of patients designated a family member as their surrogate. In most cases, having more conversations about end-of-

life issues did not increase surrogate knowledge of patients' values or preferences. Surrogates wanted written and oral instructions more often than patients wanted to provide them (62% vs. 39%,  $p < 0.001$ ). Knowing the patient's wish to stop treatment in the present condition was more important to most surrogates than the physician's recommendation to stop treatment (62% vs. 45%,  $p < 0.001$ ). Compared to patients, surrogates were less likely to want to prolong the patient's life if it entailed suffering (12% vs. 23%,  $p < 0.01$ ) and were more concerned about being certain before stopping life-sustaining treatments (85% vs. 77%,  $p < 0.02$ ).

- <sup>34</sup> Elliott JA, Olver IN. Perceptions of "good palliative care" orders: a discursive study of cancer patients' comments. *J Palliat Med.* 2003;6(1):59-68. [PMID: 12710576](#). [Full text](#)

Semi-structured interviews with 23 oncology-clinic outpatients, focused on end-of-life decision making, were analyzed. Most patients were unfamiliar with the term GPC orders, preferring the familiar "do-not-resuscitate" orders. GPC orders were negatively perceived as vague, beyond the individual's control, implying dependency on others, and failing to reduce suffering. Positive perceptions of GPC orders saw them as counteracting the impersonality of medical procedure and asserting the value of the whole patient within a social context.

- <sup>35</sup> Phipps E, True G, Harris D, Chong U, Tester W, Chavin SI, Braitman LE. Approaching the end of life: attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *J Clin Oncol.* 2003;21(3):549-554. [PMID: 12560448](#). [Full text](#)

68 African-American and white patients with stage III-B or IV lung or stage IV colon cancer and 68 patient-designated family caregivers were interviewed. White patients were more likely to have a durable power of attorney (34% v 8%,  $P = .01$ ) and were more likely to have a living will (LW; 41% v 11%,  $P = .004$ ) than were African-American patients. More African-American than white patients desired the use of life-sustaining measures (cardiopulmonary resuscitation [CPR], mechanical ventilation, tube feeding) in their current condition (all  $P > .12$ ). In a near-death condition, African-American patients were more likely than white patients to desire each of the life-sustaining measures (all  $P < .004$ ). There was no patient-caregiver agreement beyond chance regarding preferences for initiation of CPR, tube feeding, or mechanical ventilation in the patient's current condition or in the near-death condition. In the near-death condition in patients without LWs, there was disagreement in 46% of patient-caregiver pairs about CPR, in 50% about mechanical ventilation, and in 43% about tube feeding.

- <sup>36</sup> Tolle SW, Tilden VP. Changing end-of-life planning: the Oregon experience. *J Palliat Med.* 2002;5(2):311-317. [PMID: 12006234](#). [Full text](#)

Public education through the news media has proved to be a vital component of Oregon's process of change. The impact of media coverage is complemented by continuing education for health professionals. Special efforts are still needed to improve access to the Physician's Orders for Life-Sustaining Treatment program (POLST) for some rural, minority, and pediatric populations and for persons living at home with a diagnosis other than cancer.