

Advance Care Planning

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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 should be a routine part of standard medical care and, when possible, conducted with the proxy decision maker present. 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 directives, and application of the wishes when needed. The steps can be integrated flexibly 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 of which to be aware.

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WHAT IS ADVANCE CARE PLANNING?

Advance care planning is a process, not an event. 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.¹

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 do so themselves.²

Ideally, advance care planning is a process of structured discussion and docu-

mentation woven into the regular process of health care that is reviewed and updated on a regular basis.³ 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.^{4,5} In the case of a child, 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.⁶ The sense of control and peace of mind that this process fosters in the patient and the reduction of anxiety in 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 ensure 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 among the patient, proxy, and physician in several ways. The invitation to

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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 (eg, planning for bequests, autopsy, burial or cremation, funeral or memorial services, and guardianship and choices of caregivers and settings for care).

INVOLVEMENT OF OTHERS

The physician plays an important role in initiating and guiding advance care planning. The physician needs to be involved in some, but not all, stages of advance care planning 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. However, as the physician will be responsible for the actual medical orders, sufficient involvement is necessary for the physician to feel comfortable and able to pursue the goals and priorities for care that the patient wants.

Many physicians are concerned that advance care planning is too idealistic or time intensive to include it in their busy practice.

This article provides a framework for the routine and practical inclusion of the process into practice. The patient, proxy, and family can perform 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 ad-

vance care planning can be incorporated into the coding of complexity of the encounter.

Some physicians choose to have other members of the health care team assist them with advance care planning (eg, a nurse, physician assistant, or social worker). 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 permit these discussions to be to the point and effective. Once the core discussion has taken place, the patient should be invited to reflect on things and to 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, too. Determine how a patient and family want medical information to be shared and medical decision making to be handled early in the therapeutic relationship.

Terms used in advance care planning can be confusing. *Advance directives* are previous directives by the patient for his or her own health care. Advance directives fall into 2 categories, those concerning instructions for medical care and those concerning designation of 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.

FIVE 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. 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.

In the face of life-threatening illness or other significant change in health status, advance care planning becomes even more necessary. Try to find a time when there is as much stability and adjustment to the new illness circumstances as possible.

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.

Although some patients will be more likely to need advance care planning than others, healthy people who experience an unexpected illness, such as major trauma, can suddenly be the patients most in need

of advance directives. Whenever possible, physicians routinely should initiate the advance care planning process with every adult patient in their practice, regardless of age or current state of health. An outpatient office visit or other nonthreatening setting is ideal.

For children with a chronic illness, the optimal timing of advance care planning will vary. At a minimum, the discussion should take place after a relapse of disease, or at the time of significant complications, but before the child is in a state of crisis.

When introducing the topic, inquire how familiar the patient is with advance care planning. Some patients may already have advance directives in the form of a living will or durable power of attorney for health care. If this is the case, review the documents and amend them if appropriate. An advisory medical directive can be used to amend existing statutory documents.

Before beginning the process, be prepared to explain the purpose and nature of 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.

Although 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.

As patients frequently wish to minimize the decision-making burden for family, suggest that the pa-

tient involve family members, friends, and even members of the community to explore how best to 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. 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 convey the information patients need and to elicit relevant preferences to determine their advance directives. To prevent any misunderstanding, remind the patient that it is the goal of advance care planning to plan for the potential loss of his or her capacity to make decisions, temporarily or permanently. Convey commitment to follow the patient's wishes and to protect the patient from unwanted treatment or undertreatment, and convey intent to help plan for any caretaking needs of the patient's family.

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 involving 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, 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. Although these possibilities often coincide, they may not, and it can be very helpful for the patient to decide which standard is most important.

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 or her own judgment based on the situation and what he or 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. 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 op-

tions (eg, life support on a ventilator may be needed for a short time only if the underlying problem is reversible). Remind them that any intervention can be refused or stopped if it is not meeting overall treatment goals. Because recovery cannot always be predicted, help patients to consider situations involving uncertainty, incomplete recovery, or even death.

Elicit the Patient's Values and Goals. Develop an understanding of the patient's values and goals related to health and illness. For pediatric patients, involve them to the level at which they are comfortable and work with the parents or guardians. There are a number of ways to facilitate this part of the discussion. Ask about past experiences—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 or 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.

Use a Validated Advisory Document. To guide the discussion and capture patient preferences, consider using a worksheet or other carefully developed and studied tool. 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 or nonuse of interventions can become clearer. Proxy decision makers can be identified and their roles defined.

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 lifesaving 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 needs to consider the issues of cardiopulmonary resuscitation and the role of intensive care units. The patient with end-stage renal disease must consider dialysis. The patient with advanced acquired immunodeficiency syndrome needs to consider dementia and respiratory failure.

A number of validated worksheets are available from which to choose.⁷⁻⁹ 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 made some decisions, to avoid the possibility of a directive that cannot be implemented, 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 in-

formation needed to make clinical decisions.

After a final review is complete, ask the patient to confirm his or her wishes by signing the directives. 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.

Enter Directives Into the Medical Record. Once the directives have been reviewed and accepted, the physician must document them formally 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, the physician should 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 the 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.

Recommended Statutory Documents. For added protection, patients should be encouraged to complete one or more statutory documents (eg, 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 providers as appropriate. Use wallet cards to help ensure that information is available when it is needed.

Include Advance Directives in the Plan of Care. Once preferences have been established, 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 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 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 to 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 his or her 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 previous 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. Although situations where the patient is unresponsive are obvious, if the patient has some ability to respond, the physician first must determine the patient's capacity to make decisions.

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 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 to 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 logic. For instance, a decline of less invasive interventions has been shown to predict decline 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 that he or she would decline intervention in a better-prognosis scenario, there is a high probability that he or she would also decline if the prognosis were poor.

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.

Proxy Not Present for Discussions

Do not leave the proxy decision maker(s) out of the initial discussions with the patient.

Unclear Patient Preferences

Vague statements can be dangerously misleading. 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.

Discussion Focused Too Narrowly

Avoid isolated do-not-resuscitate discussions; they often create chaotic emotions and thoughts in patients who have to imagine imminent death to make the decision. A do-not-resuscitate discussion is usually an indication that other palliative goals and measures should be considered in the context of a range of scenarios.

Communicative Patients 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, the advance directive and tangible evidence of the patient's current wishes should be taken into account.

Advance Directives Not Read

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.

COMPLEMENTARY APPLICATION OF THE MODEL FOR ADVANCE CARE PLANNING TO PREPARE FOR LAST HOURS 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. Although 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 not discussed or 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.

The 5-step model for eliciting, documenting, and following advance directives can be used to guide these decision-making processes and to 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, ie, the patient, the family, and the caregivers. Personal expectations, agendas, fears and 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 or 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 do not will help to allow each to participate as closely as makes him or her comfortable.

Advance Practical Planning

Many patients will choose to get their financial and legal affairs in or-

der, give gifts, and plan for bequests, organ donation, autopsy, burial or cremation, their funeral or 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. 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 ideally should have the opportunity to be family first, and caregivers only if 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 if they are not getting enough of a chance to finish their personal business with the patient.

Choice of Setting

The choice of care setting for the last hours of the patient'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 should provide them with opportunities for privacy and intimacy. Although dying at home may be the wish of many patients, such a choice may expose family members to undue burden or compromise their careers, personal economic resources, or 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 or proxy participation, and use of a worksheet or structured materials to foster discussion and documentation.

The process also has pitfalls of which to be aware. Vague or misleading statements of wishes can be hazardous; failure to involve the proxy risks discord around decisions; premature activation of the di-

rective when the patient is still competent fails to honor the patient's real-time autonomy; and assumption about wishes in advance directives being for nonintervention may not be accurate.

The following are the key points:

- Every person has the right to participate in the planning of his or her health care.
- Consider using a validated worksheet to guide discussions. Patients, families, and proxies can complete them at home after they have been introduced.
- Revisit the subject of advance care planning on a periodic basis, particularly with major life or health changes.
- Do not presume that patients who are very ill lack the ability to make decisions.

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