

FIVE STEPS TO ADVANCE CARE PLANNING

Step 1. Introduce the topic

- Advance care planning is most easily accomplished during stable health
- Patients in need of advance directives can include both:
 - Patients with known illnesses, and
 - Healthy people who experience an unexpected illness or major trauma
- Whenever possible, routinely initiate the advance care planning process with every adult patient in your practice, regardless of age or current state of health
- An outpatient office or other non-threatening setting is ideal
- In the face of significant change in health status, try to find a time when there is as much stability and adjustment to the new illness circumstances as possible
- For pediatric patients with a chronic illness, the optimal timing of advance care planning will vary...
 - At the time of relapse of disease
 - At the time of significant complications
 - Before the child is in a state of crisis

Physician Concerns and Patient Preferences

- Physicians often have a number of concerns
 - Concern about frightening the patient or sending the "wrong message"
 - Uncertainty about the most effective approach to use
- In fact, research shows that...
 - Most patients welcome the opportunity to discuss their preferences with their physician
 - However, most patients believe that it is the physician's responsibility to start advance care planning and will wait for the physician's initiative
 - Physicians who routinely engage in the process find it helpful and not too time consuming
- There are legitimate cultural, ethnic, and racial 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
 - Determine early in the therapeutic relationship how a patient wants
 - Medical information to be shared
 - Medical decision-making handled
- 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, 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 undertreatment
 - Desire to help plan for any care taking needs of the patient's family or significant others

Determine Patient Familiarity with Advance Care Planning

- 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. (See Step 3)

Explain the Process

- Before beginning the process, be prepared to explain the goals and the process that you recommend
- 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

Determine Comfort Level

- 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

Determine the Proxy

- Patients frequently wish to minimize the decision-making burden for family
- Suggest that the patient involve a variety of people to explore how to best manage potential burdens, including...
 - Family members
 - Friends
 - Members of the community
- 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: Involve the Proxy in Advance Care Planning

- Why should the proxy decision maker be involved in advance care discussions and planning?
 - So that he or she can have a thorough and explicit understanding of the patient's wishes
 - To ensure a common understanding that can be invaluable if the proxy and physician are later called on to collaborate in decision-making
- What is the appropriate role for the proxy during the initial discussions?
 - Listen
 - Take notes
 - Ask questions for clarification

Involve the Proxy in Future Medical Care 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
 - Try to decide according to the patient's best interests
 - Decide by taking into consideration the interests of all parties that the patient cares about (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 standard and 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

Purpose of Patient/Proxy Education

- At the core of advance care planning is:
 - The empowerment of the patient (or parents if the patient is a child)
 - The preparedness of the 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
 - The benefits and drawbacks of the various treatment options
- Therefore, the discussion should provide insight into...
 - Types of clinical scenarios that might arise
 - Types of decisions that proxies most commonly face

Important Components of Patient/Proxy Education

- Define key medical terms using words the patient and proxy can understand
- Explain the benefits and burdens of various treatment options (e.g., 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
- Because recovery cannot always be predicted, help patients to consider situations involving:
 - Uncertainty
 - Incomplete recovery
 - Death

Strategies for Facilitating Discussion of Values and Goals

- There are a number of ways to facilitate a discussion of the patient's values and goals related to health and illness...
 - Ask about past experiences, including...
 - the patient own
 - 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. See Module 7: Goals of Care

Responding to the Patient

- 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 Module 2: Communicating Bad News

Using Worksheets

- Guide the advance care planning discussion
- Identify the patient's values and attitudes regarding health and medical care across a range of:

- Medical situations
- Possible goals
- Treatment choices
- Capture patient preferences
- Clarify the patient's personal threshold for use/nonuse of interventions by going through various scenarios and options
- Identify and define the roles of proxy decision-makers

Essential Components of Advisory Documents

- In all cases, the worksheet should...
 - Include a range of potential scenarios that patients should consider
 - Elicit the patient's values and goals related to health and medical care in general terms
 - 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...
 - The patient with end-stage cardiomyopathy 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

Advantages of Worksheets

- A number of validated worksheets are available to choose from
- Worksheets provide a consistent approach
- Worksheets are easy to use
- Worksheets reduce the chance that important information will be left out or framed in a biased way
- The preferences worksheets 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
- Worksheets may also be able to serve as a formal advisory document

Step 3. Document Patient Preferences

Review 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

Formalize the Directives

- 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 will avoid ambiguity

Enter Directives Into the Medical Record

- Once the directives have been reviewed and accepted, the physician must formally 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, 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 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 action:
 - Offers reassurance to the patient
 - Helps to ensure the physician's and proxy's involvement in eventual decision-making

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
- Resources for obtaining information about state-specific advance directive statutory requirements include:
 - Hospital legal counsel
 - State attorney general's office
 - 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 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 room or be hospitalized again, appropriate alternative arrangements may be needed, including:
 - Referral to a home hospice agency
 - Provision of appropriate medications
 - Instructions detailing how to handle symptoms and crises
- Practical suggestions may be helpful. Consider posting telephone numbers by the home telephone to call in an emergency (e.g., the hospice nurse on call), or numbers not to call (e.g., 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
 - Update the documents
- Major life events may affect a person's attitude toward their health care and/or end-of-life care. These include:
 - Illness
 - Marriage
 - Birth of a child
 - Death of a loved one
- Any changes in preferences warrant discussion to:
 - Allow the patient to reassess
 - Ensure that the physician and proxy decision-maker fully understand the new wishes
- Changes in preferences should be documented
- Existing documents should be updated and shared appropriately

Step 5. Apply Prior 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

Determine the Patient's Capacity to Make Decisions

- 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 Module 7: Goals of Care)

Read the Advance Directive

- 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

Interpret the Advance Directive

- 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

Consult with the Proxy

- 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

Guidelines for Extrapolation

- Certain patterns of decisions have high predictability and follow logically
- For instance, a declination of less invasive interventions has been shown to predict for 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

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

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