KEY STEPS IN MAKING AND IMPLEMENTING HEALTH CARE DECISIONS

Introduction

Steps in health care decision making

Health care decision making– including that associated with end-of-life care– involves ethical, legal, and clinical issues. Patients and families must consider philosophical concepts, medical facts and opinions, and relevant laws. To make and implement appropriate decisions, they often need professional input or assistance.

Health care decision making (including end-of-life issues) involves certain basic steps, no matter where the care occurs. Each step–for example, identifying a primary decision maker or establishing current condition and prognosis– is important to the overall result, to ensure that individuals receive care that is consistent with their values and wishes.

The accompanying table offers a framework for the ethics decision making process. It organizes key steps in end-of-life decision making into several "clusters," as follows:

- identify and obtain existing care instructions
- clarify relevant medical issues
- define decision making capacity
- identify the primary decision maker
- certify the existence of any qualifying conditions
- define and present relevant health care issues
- update care instructions, as needed
- implement choices related to health care decisions
- review situation and continue or modify approaches, as appropriate

Implementation challenges

Implementing the steps can be challenging. But shortchanging the process may reduce the chances of ensuring relevant care for each person.

Institutional (hospitals, nursing homes, etc.) or residential care settings can incorporate this information into organizational policies and procedures. Depending on the setting, they can assign appropriate staff to fulfill responsibilities such as obtaining copies of advance directives or documenting decision making capacity. Implementation of this process will require awareness of the right of providers, under the provisions of the Health Care Decisions Act, to decline participating in any procedure to which they have a conscientious objection. In the community, attaining an organized approach is considerably more challenging. Also, some details that are relevant to institutional settings (for example, the requirement for a Patient Care Advisory Committee (PCAC) may not apply in community settings.

Why the public should be aware

In all settings, the public can benefit from knowing what should be happening in regard to end-of-life decision making. Depending on the setting, they may need to advocate diligently to get the information and support they need to make and implement decisions. It should help to know what questions to ask and what answers one has a right to expect.

MAKING AND IMPLEMENTING DECISIONS RELATED TO END-OF-LIFE CARE

Key Steps	Rationale
Identify and obtain existing care instructions	
- Identify and obtain existing information regarding an individual's health care decisions and other evidence of their values and wishes	- Some individuals have already participated in advance care planning and have considered and/or documented wishes - Evidence of prior decisions and documentation is relevant to subsequent decisions about testing and treatment
- Explain rights to advance care planning and to make advance directives, if desired	- Federal and state laws and regulations require health care providers to inform individuals of their right to make advance directives, although they are not obliged to do so
- Ask about existing documents	- The federal Patient Self-Determination Act (PSDA) requires providers to ask individuals about prior documentation of treatment choices or wishes
- Obtain copies of existing documents - Transfer copies of documents to those needing them - Place documents in the medical record	- Practitioners, nursing units, Emergency Medical crews, etc. may need to review documents
- Review and clarify existing documents	- Written documents may be general, vague, or incomplete, or may place conditions on implementation of specific choices - People may not know fully what their documents say or imply, or what the documents don’t cover
- Clarify the individuals values and goals	- Written advance directives may not exist, or may be limited in scope - A person’s general values and goals can often be extrapolated from more limited information and by discussion with the individual or a knowledgeable friend or relative
Clarify relevant medical issues	
- Clarify the individual's current medical situation (what are active illnesses, problems, conditions?)	- Identifying an individuals conditions, illnesses, problems, and risks is a vital foundation for understanding the relevance and risks of various interventions and for recognizing factors affecting decision making capacity
- Establish prognosis (for example, how likely is the individual to stabilize, improve, decline, die, etc.?)	- It is often possible to establish a most likely course or outcome, which can help clarify the relevance of potential treatments

Key Steps	Rationale
Define decision making capacity	
- As appropriate, inquire about previously identified decision making capacity status	- Decision making capacity is"three dimensional," it is best evaluated across time, not just at one moment - Prior evaluations may have led to similar or different conclusions about the individual's decision making capacity; significant changes should be confirmed or discrepancies should be reconciled
- Define or confirm an individual's decision making capacity	- Clarifying decision making capacity is essential to optimizing individual participation in health care decisions, and is the basis for identifying a primary decision maker - Decision making capacity is a functional, not a medical capability, although it is influenced by medical conditions - Decision making capacity is not"all-or-none," it has several levels
- Reconcile diverse opinions about decision making capacity	- Conclusions may depend on the criteria or assessment tools that are used - It is important to have one operating perspective about an individual's decision making capacity at a given time
- Identify and address factors affecting decision making capacity	- Underlying causes of lethargy, confusion, delirium, etc. often affect decision making capacity; some of these causes can be prevented, modified, or corrected
- Certify extent of decision making incapacity	- A physician is not necessarily the best individual to evaluate decision making capacity or the only person who should do so, but the physician must at least confirm conclusions reached by others - The Health Care Decisions Act (HCDA) requires that a physician certify an individual's lack of decision making capacity
- Document the basis for conclusions about decision making capacity	- Standardized criteria have been published - Different evaluators may use diverse criteria - This information may be referred to at much later, making it important to know how a conclusion was reached
- Reassess or confirm decision making capacity periodically	- Decision making capacity may change with time, as new medical conditions or other factors arise - Periodic reappraisal, as needed, should occur both in the community and after admission to a residential or health care facility

Key Steps	Rationale
Identify the primary decision maker	
- Define the individual's role in making health care decisions, based on decision making capacity determinations	- The patient will play a more or less substantial role, depending on the degree of decision making incapacity - Some people who are capable of making health care decisions may wish to have others involved
- Identify an appropriate primary decision maker– either the patient or someone else	- Designation of a primary decision maker must follow the succession listed in Maryland's Health Care Decisions Act
- Guide a substitute decision maker regarding his/her roles and responsibilities	- A primary decision maker will need to communicate with other family members or other appropriate interested parties - The patient may still be able to participate in some discussions and decisions even if someone else is the primary decision maker
- Document the primary decision maker and the basis for his/her designation	- It is important to show that a substitute decision maker was chosen based on following an appropriate sequence, especially when decision making succession is complicated or contested
Certify the existence of any qualifying conditions	
- Identify whether the individual is in a terminal, end-stage, or persistent vegetative state	- The Health Care Decisions Act defines these categories - Some advance directives are only triggered by specific criteria such as the presence of a qualifying condition
- Have a physician certify that the individual has a qualifying condition (terminal, persistent vegetative state, or end-stage condition) where required by Maryland law	- The HCDA requires physician verification that these specific situations exist, as the law defines them
- Document the basis for conclusions that qualifying conditions exist	- Various individuals or agencies may need to know the basis for such determinations
Define and present relevant health care issues	
- Offer support for advance care planning, or refer to appropriate or preferred individuals	- Laws and regulations require offering some guidance - Many individuals need information and assistance to make or update treatment choices - People may wish to discuss these issues with trusted individuals (friends, clergy, etc.)

Key Steps	Rationale
- Define relevant issues needing discussion or decisions	- It is important to define the issues correctly before trying to address them - Examples include the scope of the individual's decision making capacity, possible need to compensate for inadequate food intake, potential benefits and drawbacks of cardiopulmonary resuscitation, ability to consent to procedures, etc. - CPR status should not be confused with wishes about treatment prior to cardiopulmonary arrest - It is possible to desire interventions prior to a cardiac arrest but to not want CPR
- Clarify the individuals goals, wishes, and values, as best as possible	- These may or may not be identifiable or clear, depending on existing documents and previous communications
- Identify the pertinence of various treatment options	- "Pertinence" relates to the individual's overall condition and prognosis, available treatments, treatment goals, overall patient goals, and presence of conditions or risks that may affect the results
- Present information to help a patient and/or substitute decision maker understand the pertinence of various treatment options	- How the information is presented may strongly influence a decision maker's understanding and the appropriateness of their decisions - The literature identifies more and less successful ways to present such information
- Certify situations where treatment is considered medically ineffective	- The HCDA defines "medically ineffective" treatments as those that would not prevent or reduce the deterioration of the individual's health or prevent his or her impending death - A health care practitioner is not obliged to provide a treatment that he/she considers medically ineffective, as defined by the HCDA - For many individuals, potential treatments would not prevent or reduce the deterioration of his/her health or prevent impending death - The literature contains evidence about how certain interventions (for example, cardiopulmonary resuscitation [CPR] or tube feeding) are likely to affect outcomes in various situations - The HCDA identifies a process to follow when treatment is determined to be medically ineffective
- Document relevant supporting information	- At future times, various individuals or agencies may need to know the basis for decisions

Key Steps	Rationale
Update care instructions, as needed	
- Obtain and document additional written or oral instructions periodically or as required by specific situations - Review or confirm decision making capacity prior to accepting changes or revocation	- This should be done in a time frame that is relevant to the individual's prognosis, condition, and wishes - Sometimes, new or revised care instructions are needed in order to implement treatment choices or because of changing situations, or because of vague or incomplete advance directives - Oral instructions must be witnessed and documented - Individuals have the right to change or revoke their advance directives - An individual's decision making capacity may change with time, and thereby affect their subsequent capacity to understand and respond appropriately to situations - The extent of decision making capacity needed to understand and make treatment choices may depend on the issue that is to be decided
Implement choices related to health care decisions	
- Obtain treatment decisions from the primary decision maker	- The appropriate primary decision maker should be consulted - The choices made by a substitute decision maker should reflect the patient's values and wishes as closely as possible - Obtain specific consent regarding withholding or withdrawing of life-sustaining technologies
- Obtain medical orders to implement treatment and care choices	- Medical orders are needed to implement specific choices to withhold or withdraw treatments - Medical orders should be consistent with a patient's or substitute decision maker's choices, or differences should be justified (for example, if a treatment requested by a patient or family was considered to be medically ineffective)
- Implement specific interventions that incorporate these decisions	- Orders should be as explicit as needed to ensure they are understood and carried out correctly and consistently - For example, provide relevant aspects of a palliative care plan; that is, what exactly will be done or will not be offered - Not everyone will interpret general terms such as "comfort care" or "palliative care" in exactly the same way

Key Steps	Rationale
Review situation and continue or modify approaches	
- Re-evaluate the individual's situation periodically, including condition and prognosis - Continue or adjust approaches depending on individual response, relevance of interventions, etc.	- An individual's situation may change with time, or the individual or substitute decision maker may change their understanding or wishes about treatment choices - This should be done in a time frame that is relevant to the individual's prognosis, condition, and wishes
- Obtain consultative support and/or refer cases to the Patient Care Advisory Committee (PCAC), as needed	- Various individuals (clergy, patient advocates, etc.) may help explain situations and obtain effective decisions - Maryland's Patient Care Advisory Committee Act requires that health care institutions have, or have access to, a PCAC - Often, the PCAC can support staff, practitioners, patients, and families who must make difficult decisions