## Table of Contents

- Introduction for the Learner (Resident/Oncology Fellow) .................................................. 2
- Introduction for Clinical Faculty Evaluator .............................................................................. 2
- Part 1: Learning Objectives ...................................................................................................... 3
- Part 2: Teaching Outline ........................................................................................................... 4
- Part 3: Evaluation Checklist ..................................................................................................... 10

**Establishing Treatment Goals:**

**Advance Directives and Advance Care Planning**
Introduction for the Learner (Resident/Fellow)

Prior to your evaluation of competency:
- Complete the web-based palliative care training program “Medical Resident Training in End-of-Life and Palliative Care” before you undergo this competency assessment. The training program is available on the UMMS Intranet, click on Physicians. The course is listed under “Helpful Links.” It is also available via the internet at http://134.192.120.12/canRes/htdocs/login.asp
  - Review Unit V (Ethical and Legal Issues), Modules 1 (Ethical Principles) and 2 (Case study) of the Web-based palliative care training program.
  - Review Part 1 (Learning Objectives), Part 2 (Teaching Outline) and Part 3 (Evaluation Checklist) THOROUGHLY so that you are aware of what is required of you.
- When you think you are suitably prepared for testing your competency in this area, ask the attending physician on your inpatient clinical rotation to evaluate the selected competency when the appropriate clinical situation arises.
- Ascertain that the attending/faculty member is certified to conduct the Palliative Care Competency Evaluation.

Field evaluation of competency:
- During the course of a clinical rotation, it is anticipated that you will have opportunities to demonstrate your competency in Establishing Treatment Goals: Advance Directives and Advance Care Planning with regard to palliative and end-of-life care during morning work rounds with your attending, and also throughout the day or during times of night call or cross-coverage.
- Identify a faculty member to evaluate your competency – current service attending recommended, if s/he is certified to conduct evaluation. ASK FACULTY MEMBER TO REVIEW THIS COMPETENCY ASSESSMENT TOOL PRIOR TO YOUR PERFORMING THIS TASK SO THAT THEIR MEMORY WILL BE REFRESHED AS TO THE DESIRED CHARACTERISTICS OF PERFORMANCE THEY WILL BE EVALUATING during the course of the rotation.
- At the end of the rotation, the Clinical Faculty Evaluator completes the Evaluation Checklist (Part 3) of this document, and shares it with you.
- You will also complete the self-evaluation portion of the checklist as a measure of competency in practice based learning.
- Evaluation Checklist must be signed by faculty and Resident.
- Return Evaluation Checklist to Dr. Susan Wolfsthal, Internal Medicine Residency Director or Dr. Heather Mannuel, Hematology/Oncology Fellowship Director.

Introduction for the Clinical Faculty Evaluator

How to perform this competency assessment:
A Medical Resident or Oncology Fellow has requested that you assess their competency in a selected palliative care domain during the time you are the attending physician on this service. To assist you with this evaluation, please do the following.

Preparing for field evaluation of competency:
- Review this Competency Assessment Tool thoroughly including the Learning Objectives (Part 1), Teaching Outline (Part 2) and Evaluation Checklist (Part 3) prior to pre-discussion counseling with Resident (required).
- Review Unit V (Ethical and Legal Issues), Modules 1 (Ethical Principles) and 2 (Case study) of the Web-based palliative care training program. The training program is available on the UMMS Intranet, click on Physicians. The course is listed under “Helpful Links.” It is also available via the internet at http://134.192.120.12/canRes/htdocs/login.asp (Optional)

Format of competency evaluation:
During the clinical rotation
- Based on the Learning Objectives (Part 1), Teaching Outline (Part 2), and Evaluation Checklist (Part 3) of this document and the content in Unit II, Module 5 of the palliative care training website, assess whether the Resident or Fellow meets the Learning Objectives during the course of this clinical rotation.
- Provide constructive feedback to Resident or Fellow throughout the rotation regarding this competency.

End-of-rotation feedback
- Review strengths and weaknesses of competency evaluation with Resident/Fellow.
- Provide constructive feedback to improve Residents/Fellows’ performance and patient outcomes.

Complete Evaluation Checklist (Part 3 of this document)
- Share with learner; allow learner to make his/her own self-assessment of performance.
- Faculty and Resident/Fellow must sign this Evaluation Checklist (Part 3).
- Learner is responsible for returning Evaluation Checklist to Dr. Wolfsthal (Residents) or Dr. Mannuel (Fellows).
Part 1: Learning Objectives

Note to learner and Clinical Faculty Evaluator: The Learning Objectives are listed in terms of fulfilling the six ACGME core competencies, listed below; these are reflected in Evaluation Checklist in Part 3 of this document.

LEGEND to ACGME core competencies: http://www.acgme.org/Outcome

<table>
<thead>
<tr>
<th>OBJECTIVES –</th>
<th>ACGME Competencies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PC</td>
</tr>
<tr>
<td>A competent Medical Resident or Oncology Fellow will be able to:</td>
<td></td>
</tr>
<tr>
<td>Describe the steps of the advance care planning process, such as the 5-step process outlined in this document.</td>
<td></td>
</tr>
<tr>
<td>Describe the role of patient, proxy, physician, and others, and the legal terms used in the State of Maryland, and at the VA Medical Center.</td>
<td></td>
</tr>
<tr>
<td>Distinguish between statutory and advisory advance care planning documents.</td>
<td></td>
</tr>
<tr>
<td>Identify pitfalls and limitations in advance care planning.</td>
<td></td>
</tr>
<tr>
<td>Utilize advance care planning to help the patient put their affairs in order.</td>
<td></td>
</tr>
<tr>
<td>Apply the 5-step approach outlined in this document (or similar structured approaches) to elicit, document, and (as the clinical case allows) follow advance directives of a patient under your care during a clinical rotation.</td>
<td></td>
</tr>
</tbody>
</table>

Part 2: Teaching Outline for Learner and Clinical Faculty Evaluator (From Weissman, et al.1)

Portions of this outline were adapted from Emanuel LL, Ferris FD, von Gunten CF, Von Roenn J, EPEC-O: Education in Palliative and End-of-Life Care for Oncology, © The EPEC Project, TM Chicago, IL, 2005

Introduction

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. 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. 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. 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 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.

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. 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.

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.

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). 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. Determine how a patient and family want medical information to be shared and medical decision making handled early in the therapeutic relationship.

Definitions

Terms used in advance care planning can be confusing.

Advance directives are prior directives from the patient for his or her health care for use at a time when the patient can no longer make decisions.

Decision making capacity is the ability to understand and appreciate the nature and consequences of health care treatment decisions.

Advance directives can be classified as statutory or advisory. Statutory documents are those that specifically adhere to a given state’s standard or laws. The UMMC booklet on Advance Directives, Informed Consent and Organ Donation contains advance directive documents that conform to the laws of Maryland. 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.

Advisory or non-statutory documents are legal. They are based on common law rights. They are supposed to reflect accurately a patient’s wishes. One example of an advisory document is a values history, which is a statement of values regarding health care in life-threatening illness situations. 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, a statutory document is recommended.
Establishing Treatment Goals: Advance Directives and Advance Care Planning

Statutory advance directives fall into two categories:

1. **Instructions for medical care.** These can be recorded in a number of types of documents:
   a. 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.
   b. 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.

2. **Designating a proxy** for the patient. In some states, the proxy is termed a durable power of attorney for health care. In the State of Maryland, a proxy so designated is officially referred to as a health care agent.

Such documents can be found in the UMMS booklet on Informed Consent and Advance Directives, which should be available on any hospital inpatient or outpatient service.

**Advisory** advance directives are instruments such as the VA’s “Advance Care Planning-Clinical Warning” note, which is a worksheet available in the notes section of CPRS that assists to identify 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. Some other validated advisory documents are listed:


**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 (Arch Int Med, 2004; 164:1501-6). 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.

Ideally, practitioners dealing with fatal illnesses such as oncologists will find that patients referred for, say, 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 physician 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.

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. 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 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 who would be the default decision-making process with the legal next of kin should the patient be too ill to participate directly (in Maryland, the default order is: court appointed guardian > spouse > adult children > parents > adult siblings > friend or other relatives). 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. 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 anticipate 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 Health Care Agent**

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 Health Care Agent 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 (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 (see CAT on “Withdrawal of Life Sustaining Medical Treatments”). 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. 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.

**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.

Who can witness an advance directive: Two witnesses who are competent adults are required. Witnesses can include members of the health care team (physician, nurse, technician). The following CAN NOT serve as a witness: 1. person named as health care agent; 2. someone who will receive money or property from patient’s estate; 3. person named as executor of patient’s estate.

**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
worksheets have been used to structure the planning discussion, the completed, finalized, and signed worksheets 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 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 (note the proxy/health care agent cannot sign as a witness of the advance directive). This offers reassurance to the patient and 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 Part A [appointment of a Health Care Agent] and Part B [health care instructions] of the UMMS Advance Directive, or at the Baltimore VAMC, the “Advance Directives-Clinical Warning” note available on CPRS – be aware – this note can only be completed by a VA social worker; recommend discussing the advisory document with the social worker prior to their discussion with the patient/family). At the VAMC, recommend working with and including the social worker in discussions of advance care planning as much as possible.

**Distribute the directive**

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). At the VA, these documents are scanned and posted on the patient’s chart. Provide copies to the patient, proxy decision maker, family members, and all health care providers as appropriate. Consider the use of 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 with terminal disease 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 (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 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. 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.

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.

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. 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.

**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.

**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.

**Advance directives do not necessarily mean that the patient wishes or should have DNR code status at the present time**

A common misconception is that if a patient has an advance directive with instructions for comfort care measures only and no life-sustaining measures in the event that death is imminent from a terminal condition, this directive is misinterpreted to mean that the patient wants DNR code status at the present time. Generally, a DNR order would be written only if the condition specified in the advance directive (death imminent from a terminal condition) is operative at the present time.

**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 nonintervention may not be accurate.

Pearl
Make a partnership with your patient and the family caregiver; draw them into the interdisciplinary team and foster their active participation in the care plan.

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.

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.

References
Fallowfield L – Communication with the patient and family in palliative medicine, pp. 333-341.
Jeffrey D. – Communication between professionals, pp. 348-353.
Pantilat SZ. Communicating with seriously ill patients: Better words to say. JAMA 2009;301(12):1279-81.

Web Sites
www.hospicefoundation.org
www.advancecareplan.com – allows people to create and register an advance care plan online; can download a PDF of the plan for $99
www.helpstartshere.org – National Association of Social Workers
www.ethics.va.gov – Advance Care Planning and Management of Advance Directives VHA Handbook 1004.02
www.healthethics.org – Advance care planning forms
### Part 3: Evaluation Checklist

<table>
<thead>
<tr>
<th>Learner name:</th>
<th>Evaluator/Attending:</th>
<th></th>
</tr>
</thead>
</table>

- **Resident PGY Level:** [ ] 1 [ ] 2 [ ] 3 [ ] 4 [ ] 5
- **Fellowship Year:** [ ] 1 [ ] 2 [ ] 3 [ ] 4 [ ] 5

**Rotation Site:** [ ] Inpatient Cancer Center [ ] Inpatient GIM [ ] Oncology Clinic [ ] Continuity GIM clinic [ ] Other

Please rate the trainee's competency/skills/knowledge/attitude using the following scales:

<table>
<thead>
<tr>
<th>For competency/skills</th>
<th>For knowledge and attitudes (e.g., Medical Knowledge)</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 = Competent to perform independently</td>
<td>4 = Superior</td>
</tr>
<tr>
<td>3 = Competent to perform with minimal supervision</td>
<td>3 = Satisfactory</td>
</tr>
<tr>
<td>2 = Competent to perform with close supervision / coaching</td>
<td>2 = Below average</td>
</tr>
<tr>
<td>1 = Needs further basic instruction</td>
<td>1 = Insufficient — needs further learning</td>
</tr>
<tr>
<td>n/o = not observed</td>
<td>n/o = not observed</td>
</tr>
</tbody>
</table>

### OBJECTIVES

**Patient Care; Interpersonal and Communication Skills**

- **Objective 1:** 4 [ ] 3 [ ] 2 [ ] 1 [ ] n/o [ ]
  - Applied the 5-step approach outlined in this document (or similar structured approaches) to elicit, document, and (as the clinical case allows) followed advance directives of a patient under your care during a clinical rotation.

- **Objective 2:** 4 [ ] 3 [ ] 2 [ ] 1 [ ] n/o [ ]
  - Utilized advance care planning to help the patient put their affairs in order.

**Overall Performance:**

<table>
<thead>
<tr>
<th>Cannot Evaluate</th>
<th>1 to 3 Unsatisfactory</th>
<th>4 to 6 Satisfactory</th>
<th>7 to 9 Superior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Medical Knowledge**

- **Objective 1:** 4 [ ] 3 [ ] 2 [ ] 1 [ ] n/o [ ]
  - Defined advance care planning and explain its importance.

- **Objective 2:** 4 [ ] 3 [ ] 2 [ ] 1 [ ] n/o [ ]
  - Described the steps of the advance care planning process, such as the 5-step process outlined in this document.

- **Objective 3:** 4 [ ] 3 [ ] 2 [ ] 1 [ ] n/o [ ]
  - Distinguished between statutory and advisory advance care planning documents.

**Overall Performance:**

<table>
<thead>
<tr>
<th>Cannot Evaluate</th>
<th>1 to 3 Unsatisfactory</th>
<th>4 to 6 Satisfactory</th>
<th>7 to 9 Superior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Practice based Learning and Improvement**

- **Objective 1:** 4 [ ] 3 [ ] 2 [ ] 1 [ ] n/o [ ]
  - Identified pitfalls and limitations in advance care planning.

**Overall Performance:**

<table>
<thead>
<tr>
<th>Cannot Evaluate</th>
<th>1 to 3 Unsatisfactory</th>
<th>4 to 6 Satisfactory</th>
<th>7 to 9 Superior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Systems Based Practice**

- **Objective 1:** 4 [ ] 3 [ ] 2 [ ] 1 [ ] n/o [ ]
  - Described the role of patient, proxy, physician, and others, and the legal terms used in the State of Maryland, and at the VA Medical Center.

**Overall Performance:**

<table>
<thead>
<tr>
<th>Cannot Evaluate</th>
<th>1 to 3 Unsatisfactory</th>
<th>4 to 6 Satisfactory</th>
<th>7 to 9 Superior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Part 3: Evaluation Checklist (Continued)

**Resident/Fellow strengths:**

<table>
<thead>
<tr>
<th>Cannot Evaluate</th>
<th>1 to 3 Unsatisfactory</th>
<th>4 to 6 Satisfactory</th>
<th>7 to 9 Superior</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>8</td>
<td>9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Overall impression:**

**Resident/Fellow self-evaluation of performance:**

---

Clinical Faculty Evaluator/Attending

Resident/Fellow

Clinical Faculty Evaluator/Attending – PRINTED NAME/DATE

Resident/Fellow – PRINTED NAME/DATE