

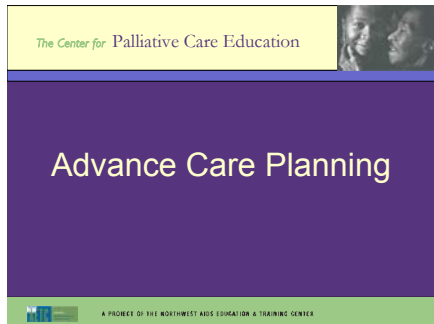
Advance Care Planning Module Contents

▶ Learning Objectives	
Advanced Care Planning	20
<hr/>	
▶ PowerPoint Care Planning Presentation with Trainer Notes	
Advance Care Planning	21
<hr/>	
▶ Skill Building & Interactive Exercises	31
EPEC Trigger Tape Exercise	32
Advance Care Planning Role Play Exercise	33
<i>Five Wishes</i> Questions	34
Values Exercise	35
<hr/>	
▶ Sample Agendas	36
<hr/>	
▶ Evaluation Forms	37
<hr/>	
▶ Suggested Handouts	42
<hr/>	
▶ Resources	43
Advanced Care Planning Resources	43
Permanency Planning Resources.....	47

Learning Objectives

At the end of this presentation, participants will be able to:

- Define advance care planning and explain its importance.
- Describe the steps of the advance care planning process.
- Describe the role of patient, proxy, clinician and others.
- Identify pitfalls and limitations in advance care planning.



Trainer Suggestion

Introduce yourself and go over the agenda for the session. If there is time in the session and a small enough group, invite participants to introduce themselves and talk about what they are hoping to learn.

Invite questions and comments throughout the presentation.

Learning objectives

- Define advance care planning and explain its importance
- Describe the steps of the advance care planning process
- Describe the role of patient, proxy, clinician, and others
- Identify pitfalls and limitations in advance care planning

Slide Note

In addition to gaining content knowledge about advance care planning, clinicians also need to be comfortable talking about end-of-life issues in order to have an effective conversation with a patient. In addition to a lecture about advance care planning, we will also be practicing the skills and sorting out our own ideas and feelings about end-of-life planning.

Trainer Suggestion

This would be a good spot to do the EPEC Trigger Tape Exercise on Advance Care Planning.

Consider a case

- 65-year-old man HIV+ for 15 years
- Hx of non-Hodgkin's lymphoma, successfully treated
- On HAART with hx of cognitive side effects
- Recent hospitalization for liver failure
- No family; partner deceased

Slide Note

We'll start with a case that illustrates some of the important issues in advance care planning. This 65-year-old man has been HIV positive for 15 years. He has been on many HAART regimens, and although his current regimen is effective in keeping his viral load down, he has had cognitive side effects and was recently admitted to the hospital for liver failure. His life partner passed away several years prior, and he has no family. He has become very frail, and at hospital discharge it was suggested that he move to an assisted living facility.

Trainer Suggestion

What are some advance care planning issues that come to mind with this case?

[no obvious proxy, lack of decision-making capacity, need to make plans as health declines]

In this session, we'll consider issues related to helping him plan for his future care as his illnesses progress. First we'll define advance care planning and discuss why it is important.

What is advance care planning?

- A communication process rather than a legal process
- A way of planning for future medical care
- A mechanism for ensuring that care received matches patient's values and goals

Slide Note

Advance care planning is the process of planning for future medical care. Patients with HIV/AIDS face a high probability of severe illness, disability, incapacity, or death. Advance care planning involves helping people anticipate and plan for those events, and it is a very important function of the clinician role. These situations can be complicated and emotion-laden; thinking about them in advance helps when the events do happen.

Although advance care planning involves the discussion of legal documents, it is important to remember that a signed piece of paper is not the most important outcome of advance care planning. The communication between the patient and clinician is. One of the most important steps in this process is to elicit and to understand the patient's values and goals so as to ensure that the patient receives care in the future that is congruent with those values.

Why is advance care planning important?

- HIV/AIDS patients have an unpredictable course of illness
- Builds trust
- Helps to avoid confusion and conflict
- Permits peace of mind

Slide Note

As with the case that we discussed, often people with HIV/AIDS have an unpredictable up and down course. This is one of the reasons that starting to think about future health events is so important. Other reasons for our patient in the case include a high risk of serious decline and death at any time and a strong possibility that he might lose his decision-making capacity.

Advance care planning also helps build trust between you and the patient or client. If you can provide a safe setting in which people can talk about their goals, values, fears, and worries, that can build trust and can help solidify the relationship for all the future work that you do. For patients and providers, it can help avoid confusion and conflict, for example when a patient is admitted to the hospital and the family is asked about code status. Having made some decisions ahead of time can contribute to peace of mind. If patients know things are taken care of if a serious health event should happen, then they can live more fully in the present.

Concepts underlying advance care planning

- Advance directive
- Health care agent or proxy
- Do not resuscitate (DNR) orders
- Patient Self Determination Act

Slide Note

There are two main products of advance care planning:

The advance directive is a set of specific instructions about one's wishes under potential future circumstances. This document is called a Living Will in many states.

The proxy is a person appointed by the patient to make decisions when the patient is too sick to make or communicate his or her own decisions. The proxy does not decide for the patient, but rather does the best she or he can to speak in the patient's voice, honoring the patient's values and goals. A common document used to appoint a proxy is called a Power of Attorney for Health Care.

Another document that sometimes comes into play at end of life is the Do Not Resuscitate Order (DNR), also called the DNAR (Do Not Attempt Resuscitation) Order. This is a document signed by the clinician, rather than the patient. In the United States, the Patient Self Determination Act requires that every patient admitted to a hospital be asked about a living will. Given that in the U.S. we have this law which mandates advance care planning, all clinicians need to be prepared to talk about these things with patients: Advance directives, do not resuscitate orders, and the identification of a health care proxy.

5 steps for successful advance care planning

1. Introduce the topic
2. Structure the discussion
3. Document patient preferences
4. Review and update when clinical course changes
5. Apply directives when need arises

The EPEC Project, 1999, www.epec.net

Slide Note

In this session, we'll cover the steps you can take to help your patients and families with the advance care planning process. These suggestions were adapted from a protocol developed by the EPEC Project (Education for Physicians on End-of-Life Care), and you may wish to review some of the resources available on their Website.

Step 1: Introduce the topic

- Allow adequate time & privacy
- Ask what the patient knows: "Have you thought about having a living will?"
- Explain the process: "It's helpful for us to talk about it before making any decisions."
- Determine comfort level: "Do you feel ready to talk more about this today?"

Slide Note

Here are some suggestions to begin a discussion on advance care planning. Asking patients what they already know – "What have you been thinking about a living will?" is a neutral way to approach the topic. Explain that they can talk about the issues without having their thoughts written down immediately: "I want to hear what you have to say, and then we'll go through a process of making decisions." Ask about the patient's comfort level. There are times when you're introducing this and people really balk. If this happens, rather than pressing on, it can be helpful to schedule another time to have the discussion.

Step 2: Structure the discussion (*Five Wishes*)

- Who do you want to make health care decisions for you when you can't make them [proxy]?
- What kind of medical treatment do you want or don't want?
- How comfortable do you want to be?
- How do you want people to treat you?
- What do you want your loved ones to know?

www.agingwithdignity.org

Slide Note

Patients may not know what a living will is, or what a proxy is. It can be helpful to describe the topics that will be talked about.

This slide is based on *Five Wishes*, a document developed by an organization called Aging with Dignity. It is a generalized living will that is valid in 35 states, and it provides ways to frame advance care planning questions. It covers the legal, medical, emotional, and spiritual aspects of illness. It can be ordered from the Aging with Dignity Web site at www.agingwithdignity.org or by calling 1-888-5-WISHES. It's very important to start with the positive things that we can do. So the first question here deals with the health care proxy. Identifying a person who can make decisions for you when you can't make them for yourself is one way of giving people some control in their illness process.

Trainer Suggestion

Have participants break into pairs or small groups and discuss these questions as they pertain to themselves. See *Five Wishes Questions* exercise for more details.

Identify a proxy decision-maker

- Entrusted to speak for the patient
- Involved in all the discussions
- Must be willing, able to take the proxy role

Slide Note

The proxy decision-maker is the person entrusted to speak for the patient once the patient is unable to speak for her or himself. It's very important to try and involve this person in discussions early on. If a proxy has been identified, but has not been in on any of the discussions, they're not likely to be able to do a good job later. And the proxy has to be willing to be in this role. For some patients, having a proxy who's not their spouse can be easier. Sometimes the spouse's desire not to lose their loved one may conflict with the patient's wish not to have aggressive care.

In the case we discussed earlier, at first there did not seem to be an obvious proxy. The patient's partner had died some years earlier, his parents were dead, and he had no siblings. After some exploration with his clinician, the patient chose a long-term friend as his proxy.

Educate patient and proxy

- Define key medical terms
- Explain benefits, burdens of treatments:
 - Life-support may only be short-term
 - Any intervention can be refused
 - Recovery cannot always be predicted

Slide Note

Once the proxy is chosen, it is important to meet with the patient and proxy together. In our case, the proxy was invited to subsequent medical visits to discuss advance care planning. The initial visit with the proxy was a good time to check out the interest level of the proxy, and to provide general education about the illness, as the proxy was not very knowledgeable about the patient's condition.

It is important to have ongoing contact with the proxy and to educate the patient and proxy throughout the course of illness. Define key medical terms that you will use to talk about patient care. Explain the benefits and burdens of the treatment options, such as hydration, feeding tubes, or intubation. You might explain, for example, that life support is going to be short term, that recovery is difficult to predict, and that any kind of medical treatment can be refused at any time.

Topics to consider

- Pain management
- Artificial nutrition and hydration
- CPR
- Mechanical ventilation
- Blood transfusion
- Dialysis
- Antibiotics, HAART, other meds

Slide Note

These are some of the issues you may need to discuss, depending upon the patient's clinical status.

Elicit patient values and goals

- Ask about past experiences:
 - “Did the staff ask you about living wills when you were in the hospital last time?”
 - “What happened with that conversation?”
 - “Did your partner have a living will?”

Slide Note

Eliciting the patient's values and goals is one of the essential tasks of advance care planning. Asking about past experiences can be a good way of starting a discussion. Here are some sample questions to get the conversation started.

Trainer Suggestion

You might invite participants to offer other suggestions for opening questions or work in pairs to practice starting a discussion on advance care planning.

Elicit patient values and goals

- Use values questions:
 - “What makes your life worth living?”
 - “How would you like to spend your last days?”
 - “What are your spiritual beliefs that might affect treatment choices?”

Slide Note

There are workbooks such as Five Wishes and values exercises such as those found in *Your Life, Your Choices* that can help to facilitate a discussion with the patient about values and goals. Here are some sample questions from *Your Life, Your Choices*. There are also checklists and charts that help the patient rate different treatment choices.

Trainer Suggestion

This would be a good time to have participants do some values exercises as an example. See Values Exercise. [link]

Elicit patient values and goals

- Describe potential patient situations:
 - “Suppose you were very sick in the hospital again. Would you want our focus to be more on your comfort or on your living longer?”
 - “Suppose your liver failure progressed. Would you want to go to the intensive care unit, or would you prefer to receive care at home but risk living a shorter time?”

Slide Note

Another way to facilitate talking about treatment possibilities and further elicit the patient’s values and goals is to describe potential situations the patient might face in the future given the disease picture and progression.

Trainer Suggestion

You may want to invite participants to suggest other hypothetical situations that could be discussed, based on various patient diagnoses and illness trajectories.

Use an advance care planning document

- A number are available:
 - Five Wishes
 - Living Wills
- Easy to use
- Reduces chance for omissions
- Patients, proxy, family can take home

Slide Note

Using a planning document can be a good way to guide the discussion. It helps people write down their thoughts once they’ve begun considering their wishes. It is something that people can take home and discuss with their families. And it leaves a record of the conversation and decisions made to refer back to.

How can a clinician or patient get examples of documents to use? Sources include Websites, legal assistance programs, hospital admitting departments, and social workers.

One important note: Don’t defer this discussion just because there is no document at hand. Having the conversation is the most important part of the process; the document can come later.

Trainer Suggestion

You might have a resource list printed up for participants and also provide examples of your state’s documents. You might also provide a list of legal referrals such as legal aid clinics, AIDS service organizations, etc.

Step 3: Document patient preferences

- Review advance directive
- Sign the documentation
- Put it in the patient's chart or medical record
- Encourage patient to have copies to provide to different medical settings
 - Proxy may assist with this

Slide Note

Once people are ready to make a decision, then you want to review the document with them, have them sign it, and make sure it's in the medical record. The proxy can assist the patient in providing copies to all the medical settings that patient is involved with. Having copies at home to show an ambulance driver or home care nurse is also advisable.

An attorney is not necessary for the completing a living will or power of attorney; only a notary needs to be present to witness the patient's signature. Many hospitals have a notary available who can come to the patient's bedside. With complicated situations or where a patient's wishes or choice of proxy might be contested, an attorney would be beneficial. However, getting a lawyer should not be a barrier to making these documents.

Step 4: Review, update

- Use clinical events as triggers to review documents
- As disease progresses, allow for evolution in patient understanding and preferences
- Discuss and document changes

Slide Note

Step 4 occurs after a disease progresses and there have been clinical events – hospitalization, negative test results, new symptoms, etc. Unfortunately, in general practice, it is often the case that advance care planning first happens after a significant clinical event when the patient and family are most stressed.

When there has been a major change in the patient's health status or a significant clinical event, it is important to revisit the advance directive and make sure that the patient still has the same wishes for care. It is also a good time to review the clarity and ease of use of the current document and make changes if needed.

Step 5: Apply directives when indicated

- Review the advance directive
- Consult with the proxy
- Use ethics committee for disagreements
- Carry out the treatment plan

Slide Note

When it becomes necessary to apply the advance directive, review it with the patient if possible; otherwise go over it with the patient's proxy. The advance directive only comes into play when the patient no longer has the capacity to make a decision. Make sure the whole health care team is aware of the directive.

In the case we discussed earlier, when the patient was again admitted to the hospital, he became incoherent. It was necessary to decide whether or not to admit him to the intensive care unit and intubate him. The care team was able to look at his advance directive and talk to the proxy, and it was decided not to bring him into the ICU.

You may also find yourself in a situation where a doctor says, "The patient wrote that, but I don't want to do it." This is where clinicians can use the ethics committee in the hospital, or palliative care consultant to help negotiate. Many ethics committees have someone on call.

It's important to remember that clinical situations are complex and unpredictable, and often have features that weren't covered in the specifics of the advance directive. Sometimes it is just hard to figure out what the patient would have wanted. If the clinician and the proxy have had prior conversations with the patient about his or her values and goals, they can use those conversations to guide decision-making. The ethics committee is also a good resource in these cases.

Pearls

- Advance care planning can reduce family burden
- Family members may not be the best proxies
- Focus on what kind of care is desired rather than what should be withdrawn

Slide Note

Many family members find it difficult to make decisions for their loved ones. Knowing what their loved one thought can be very helpful and reduce the decision-making burden on families.

In some situations, family members may not be the best person to serve as a health care proxy because of their (natural) emotional involvement or because of family history. Sometimes a friend may be the better choice to serve as proxy.

It's important to remember to not start an advance care planning discussion by talking about what we won't do. Focus on what kind of care will be offered, such as pain management, rather than starting the discussion with withdrawal of life support.

Common pitfalls

- Patient reluctant to engage in ACP
- Clinician reluctant to engage in ACP
- Proxy not involved in discussions
- Patient preferences are vague or nonspecific
- Directive is applied when patient is still communicative
- Family disagrees with patient decisions

Slide Note

Some of the challenges you might encounter in advance care planning include patients' reluctance to engage in the process. In this situation, the patient may need some time to prepare for a discussion. You may also want to remind them of the benefits to them and their family of having clear directives. Another very real barrier is our own reluctance to engage in ACP out of discomfort or because we are afraid of taking away hope. It is important to remember that by having the discussion, we are empowering patients by helping them prepare for and have the best possible outcome.

It can be difficult for the health care team to make decisions if the proxy has not been present during advance care discussions. You may want to obtain written permission from the patient early on to be able to contact the proxy to update him or her.

Often when preferences are vague, clinicians make assumptions about what the patient means based on our own preferences. You may want to use a values exercise or the Five Wishes document to help patients to clarify and get specific about their preferences.

It is important to include the patient in all decisions until the patient can no longer speak for her or himself. The advance directive only goes into effect when the patient is no longer able to make her or his own decisions.

When there is family conflict or disagreement regarding patient preferences, you may want to call a family conference and utilize a social worker, mediator, or legal person.

Ultimately, we have the role of advocating for and carrying out the patient's wishes.

Common clinician assumptions

- Patient/individual autonomy
- Full disclosure for informed decision-making
- Control over the dying process
- No one should suffer
- Written, formal agreements
- Future orientation

Slide Note

The assumptions about health care that we as clinicians bring into an advance care discussion should be kept in mind. The assumptions listed on this slide are based on European-American cultural beliefs, and we need to be open to other perspectives on these issues.

Our medical system values the patient receiving complete disclosure on diagnosis and prognosis, and on them being the one to make all future decisions. A common perspective is that no one should experience pain and that we should have as much control as possible over the dying process. We want people to think ahead, and we want their thoughts in writing. We frequently ask this of people who have little reason to trust us or to trust the medical system, or who have had bad experiences either personally or historically with the system of medical care in America.

Alternative patient perspectives

- Family has obligation to shoulder the burden
- The physician is the expert and should decide
- Truth of diagnosis is harmful or burdensome to patient
- We can't control our fate; it's God's will
- All life involves suffering
- A person's word is all that is needed
- Indirect communication; present orientation

Slide Note

These are some alternative perspectives which may be related to the patient's culture or life experiences. In many cultures, it is felt that discussing death with the patient may hasten death or cause greater emotional and physical harm. Some cultures believe it is the family's responsibility to take on the burden of medical knowledge and decision-making. Other cultures believe that the physician should decide since she or he has the training and expertise.

Some people feel that illness is a test from God or a way to offer up our suffering to the will of God. Many cultures are more present-oriented, so discussing future scenarios and discussing situations directly may be considered rude and/or incomprehensible. And many people have a mistrust of the medical system and of authority, and feel uncomfortable signing forms that would allow a physician to withhold care.

Trainer Suggestion

This might be a good place to practice the protocol with some role plays. After a discussion of the role plays, follow-up with the last few slides. Also see Cross-Cultural Communication module for more on this topic.

Other topics to consider

- Autopsy
- Organ donation
- Burial / cremation
- Funeral / memorial services
- Permanency planning for dependents
- Financial, legal affairs
- Final gifts and bequests

Slide Note

These are some of the issues that may also need to be discussed with the patient or proxy. Timing and cultural sensitivity will be important in the discussion of autopsy and organ donation. People often have burial or cremation wishes, or specific wishes for funeral or memorial services. It can ease the burden on survivors if the patient's wishes are known. If there are young children involved, patients can feel a great sense of relief if they know that plans are in place for their dependents' care. Financial and legal issues also require advance planning. Having referral resources available for patients can help facilitate the planning process.

Reconsider the case

- 65-year-old man HIV+ for 15 years
- Hx of non-Hodgkin's lymphoma, successfully treated
- On HAART with hx of cognitive side effects
- Recent hospitalization for liver function problems
- No family; partner deceased

Slide Note

Let's look at our case again. The provider in this case did follow the five steps of advance care planning. After the proxy was selected, the clinician met with him and the patient. She educated the proxy on the patient's condition. She outlined likely scenarios and talked about possible treatment decisions that might need to be made along the way. She tried to find out what the patient's values and goals were for his care. The patient then completed a Living Will and discussed his preferences more fully with his proxy. The clinician revisited the topic whenever there was a change in the patient's condition. The proxy occasionally accompanied the patient to his medical appointments and was kept up to date and in the loop.

As we discussed earlier, the medical team did apply the patient's advance directive when he was admitted to the hospital with liver failure. They decided not to admit him to the ICU based on that document and after discussions with his proxy. The patient died a few days after admission. Both the clinician and the proxy felt that they had followed the patient's wishes.

Summary

- Advance care planning is a fundamental palliative care skill
- Advance care planning reduces family burden at end-of-life
- The identification of the proxy is an important goal
- The discussion is more important than the documents

Slide Note

In summary, clinicians need to be skilled at talking with patients about advance care planning. The essential elements underlying advance care decisions are the patients' values and goals, so eliciting these in discussion is critical. This process can greatly reduce the burden on families and provide peace of mind to patients.

Contributors

Anthony Back, MD	Director
J. Randall Curtis, MD, MPH	Co-Director
Frances Petracca, PhD	Evaluator
Liz Stevens, MSW	Project Manager

Visit our Web site at wpaallcare.org

Copyright 2003, Center for Palliative Care Education, University of Washington

This project is funded by Health Resources and Services Administration (HRSA) and the Robert Wood Johnson Foundation (RWJF).

Skill Building & Interactive Exercises

- ▶ EPEC Trigger Tape Exercise – *Advance Care Planning*
- ▶ Advance Care Planning Role Play Exercise
- ▶ *Five Wishes* Questions
- ▶ Values Exercise

EPEC Trigger Tape Exercise – Advance Care Planning

Type of Activity:	Observation/Discussion
Time:	20-30 minutes
Materials:	EPEC Trigger tape #1 VCR and television
Purpose:	For participants to observe and name good and not-so-good elements of an advance care planning discussion.

This exercise is to be done using the Module #1 Trigger Tape from the EPEC Curriculum. EPEC (Education for Physicians on End-of-Life Care) developed a curriculum to provide physicians with the basic knowledge and skills needed to appropriately care for dying patients. In addition to 12 training modules on palliative care topics, EPEC developed accompanying trigger tapes that provide examples of end-of-life communication skills and are used to stimulate discussion. The curriculum and trigger tapes can be ordered from their Website at <http://www.epec.net/content/products.html>.

Emanuel LL, von Gunten CF, Ferris FF, eds. “Module 1: Advance Care Planning,” *The Education for Physicians on End-of-Life Care (EPEC) Curriculum*: © The EPEC Project, The Robert Wood Johnson Foundation, 1999.

Set-up: The patient is Keith Cunningham, a 55-year-old computer salesperson who is diabetic with mild hypertension, but otherwise in good health. Mr. Cunningham has come in for a routine physical exam. In reviewing the chart, the physician notices that advance directives have not been addressed.

Discussion Questions:

1. How does the doctor bring up the subject of advance care planning?
2. What things does the physician do well? What things could he do differently?
3. In what ways does the clinician elicit Mr. Cunningham’s values and goals?
4. How does the clinician handle the issue of a proxy?
5. What cultural issues might be operating in this situation? How should the physician handle them?
6. What tools does the physician use or suggest in his discussion?
7. What plans does he make for follow-up with the patient, if any?

Advance Care Planning Role Play Exercise

Type of Activity:	Simulation/Discussion
Time:	40 minutes
Materials:	<i>Five Wishes</i> document Values Exercise PowerPoint slide of questions that elicit values and goals Living Will and Durable Power of Attorney for state where presentation is held
Purpose:	To provide participants with the opportunity to practice eliciting patient values and goals, the opportunity to practice advance care planning, and the opportunity to experience advance care planning as the patient.

Instructions:

Start by asking for a show of hands on how many of the participants have done advance care planning themselves and have advance directives. Let the group know that the majority of people do not have an actual document but most people have a fairly clear idea about what they would want and not want. Then tell the group that they will now have the opportunity to experience an advance care planning session, both as the patient and as the clinician.

Divide the group into pairs. One person will be the clinician; the other will be the patient.

1. Have the “clinician” utilize the tools presented in the lecture for eliciting patient values and goals. You can provide questions from the *Advance Care Planning* PowerPoint presentation itself, the *Five Wishes* document, and/or the Values Exercise to aid the clinician.
 2. Have the clinician help the patient to identify a proxy decision maker.
 3. Provide advance directives for the participants to use, preferably ones that are valid in the participants’ state.
 4. Have the person who is the “patient” play her or himself. This is a good way for participants to think about their own values and goals for care and is a good empathy-building experience (as well as a way for the participants to complete their own advance directives). Give permission for the person playing the patient to take on a role other than her or himself, opt out, or stop at any time.
 5. Allow 15 minutes for the pair to complete one person’s advance directives. Then allow another 15 minutes for the role players to switch roles and complete the second person’s advance directives. It is ok not to complete the documents!
 6. Monitor the dyads and be prepared to provide support if strong emotions arise.
 7. Questions for discussion:
 - What was the experience like for you as a clinician? What was it like for you as a patient?
 - What questions and statements were most helpful for you as a patient to think about your advance care planning wishes?
 - What have you learned from this experience that will help you with doing advance care planning with your patients?
 8. Wrap up the discussion by highlighting some of the important points volunteered by the participants.
- See [Role Playing as a Teaching Technique](#) for information on how to include role play in your training.

Five Wishes Questions

Type of Activity:	Discussion
Time:	20-30 minutes
Materials:	<i>Five Wishes</i> document
Purpose:	To have participants begin to think about how they would initiate a discussion with a patient regarding their end-of-life wishes. To have participants consider these issues for themselves.

Instructions:

This exercise is done utilizing *Five Wishes*, a document developed by Aging with Dignity. It is a generalized living will that is valid in 35 states, and it provides ways to frame advance care planning questions. It covers the legal, medical, emotional, and spiritual aspects of illness. It can be ordered from the Aging with Dignity website at www.agingwithdignity.org or by calling 1-888-5-WISHES.

Have participants break into pairs or small groups and discuss the following questions from *Five Wishes* as they pertain to themselves:

- Whom do you want to make health care decisions for you when you can't make them [proxy]?
- What kind of medical treatment do you want or not want?
- How comfortable do you want to be?
- How do you want people to treat you?
- What do you want your loved ones to know?

Values Exercise

Type of Activity:	Discussion
Time:	20-30 minutes
Materials:	<i>Your Life, Your Choices</i> values exercises
Purpose:	To have participants begin to understand their own values in regards to end-of-life issues. To begin to consider how they might discuss values and goals with patients.

Instructions:

Have participants do some of the values exercises found on pages 19-26 in *Your Life, Your Choices*, a workbook designed to help patients and families with developing advance directives. There are paper and pen exercises in easy checklist format to help people clarify their beliefs and values about end-of-life care. This workbook is available at www.va.gov/resdev/programs/hsrd/ylyc.htm.

Discussion Questions:

1. What did you learn from doing these exercises that surprised you?
2. How would you use these exercises in working with patients?
3. How might these exercises be useful in working with patients from different cultures? What problems might you encounter using these exercises?

Sample Agendas

We've developed sample agendas for teaching advance care planning skills. These agendas are adapted from trainings conducted by the Center for Palliative Care Education. The training module components are designed to work flexibly with each other. We encourage your experimentation in combining different components to find a training program that works for you and your audience.

► If you have one hour...

Introductions & Pre-Evaluation	<i>5 minutes</i>
<i>Five Wishes</i> Questions Exercise	<i>15 minutes</i>
<i>Advance Care Planning</i> PowerPoint	<i>25 minutes</i>
ACP EPEC Trigger Tape	<i>5 minutes showing</i> <i>10 minutes discussion</i>
Wrap Up & Evaluation	<i>5 minutes</i>

► If you have two hours...

Introductions & Pre-Evaluation	<i>10 minutes</i>
ACP EPEC Trigger Tape	<i>5 minutes showing</i> <i>10 minutes discussion</i>
<i>Advance Care Planning</i> PowerPoint w/Values Exercise	<i>25 minutes</i> <i>20 minutes</i>
Advance Care Planning Role Play Exercise	<i>30 minutes exercise</i> <i>10 minutes discussion</i>
Wrap Up & Evaluation	<i>10 minutes</i>

* Please refer to [Tips for Developing a Training Agenda](#) for more information.

Evaluation Forms

We've developed evaluation forms to use with our training modules. They consist of unique identifier information about the participant, and questions aimed at gaining information about participant satisfaction and program effectiveness. You may want to adapt these forms and questions to your own evaluation needs.

- ▶ Pre-Training Survey
- ▶ Post-Training Survey
- ▶ Follow-Up Survey

* Please refer to [Evaluating Your Training Session](#) for more information.

Advance Care Planning Pre-Training Survey

Thank you for completing this survey. Your input will help us improve our training program and will provide information about its effectiveness to guide future planning. Please answer these questions as best you can – if you're not sure of an answer, just give it your best try.

Date: ___/___/___ ID: Birth month: ___ Day: ___ Last 4 digits of SSN: _____

1. Please rank your current level of skill in the area of advance care planning by checking one of the following numbers from 1 to 5:

Need more skill for basic competency			Adequate skill			Highly skilled
1	2	3	4	5		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. What is your level of personal comfort with discussing advance care planning with a patient/client?

Extremely uncomfortable			Somewhat comfortable			Extremely comfortable
1	2	3	4	5		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Please answer the following by checking the True or False box or writing in the space provided:

- a. Once a person names a proxy in an advance directive, the proxy makes all the medical decisions. True False
- b. A lawyer is needed to complete an advance directive. True False
- c. List 3 of the 5 steps in advance care planning.

Correct Answers: 3a. False, 3b. False, 3c. The 5 steps in advance care planning are: Introduce the topic; Structure the discussion; Document patient preferences; Review and update when clinical course changes; and Apply directives when need arises.

Post-Training Survey

Thank you again for your input to help us improve our training program and guide future planning. As before, please answer these questions as best you can – if you’re not sure of an answer, just give it your best try.

Date: ___/___/___ ID: Birth month: ___ Day: ___ Last 4 digits of SSN: _____

1. Please respond to the following questions regarding this training using the scale below:

	Not at all		Somewhat		Very much
Did the training hold your interest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you learn things in the training that will be useful for your work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How understandable was the material presented to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were the educational materials, such as slides or handouts, useful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How responsive was the trainer to the audience’s questions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel the trainer’s presentation was culturally sensitive?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. What were the strengths of this presentation?

3. How could we improve this presentation?

4. Would you recommend this training to someone else? Yes No

5. Please rank your current level of skill in the area of advance care planning by checking one of the following numbers from 1 to 5:

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. What is your level of personal comfort with discussing advance care planning with a patient/client?

Extremely uncomfortable		Somewhat comfortable		Extremely comfortable
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Please answer the following by checking the True or False box or writing in the space provided:

- | | | |
|--|--------------------------|--------------------------|
| a. Once a person names a proxy in an advance directive, the proxy makes all the medical decisions. | True | False |
| | <input type="checkbox"/> | <input type="checkbox"/> |
| b. A lawyer is needed to complete an advance directive. | True | False |
| | <input type="checkbox"/> | <input type="checkbox"/> |
| c. List 3 of the 5 steps in advance care planning. | | |

8. What do you anticipate doing differently in your work as a result of this training?

9. How much did this training help prepare you to do the following:

	Not at all		Somewhat		Very much
Provide primary end-of-life care for patients with HIV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide education and training to other clinicians on end-of-life care issues?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advocate for better palliative care in your workplace?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Would you be willing to be contacted in one month for a brief follow-up? Yes No
 If yes, what is your email address? _____

11. Please write any additional comments, thoughts, or suggestions here. We appreciate your taking the time to complete these surveys. Thank you very much!

Correct Answers: 7a. False, 7b. False, 7c. The 5 steps in advance care planning are: Introduce the topic; Structure the discussion; Document patient preferences; Review and update when clinical course changes; and Apply directives when need arises.

Advance Care Planning

Follow-Up Survey

[This is a sample of a letter to send out to your training participants 4-6 weeks after the training.]

Hello!

About a month ago, you attended a presentation on Advance Care Planning, given by [presenter].

Thank you for participating in our evaluation. Your survey responses have been very helpful for planning the next steps in our training program. Thanks also for agreeing to answer some follow up questions for our evaluation. If you have a few minutes to answer the following questions, it would be very helpful.

Now that a month has gone by...

1. What changes, if any, do you feel you have made in your work as a result of this training session?
2. Please rank your current level of skill in advance care planning:
(1=Need more skill for basic competency; 3=Adequate skill; 5=Highly skilled)
3. What is your overall rating of the quality of the session you attended?
(1=Poor; 3=Average; 5=Excellent)
4. Please write any additional comments, thoughts, or suggestions here.

Please contact me [your contact information here] if you have any questions about our project or if you'd like us to keep you informed of any upcoming training sessions. Thanks again!

Suggested Handouts

1. Kelly, C. (1999). *Tips on talking to your patients about advance directives*. ACT-ASIM Observer Mar 99. Available at <http://www.acponline.org/journals/news/mar99/advdir.htm>.
2. Partnership for Caring (2001). *Talking about your choices*. Available at www.partnershipforcaring.org/Talking/talkingaboutyourchoices.html.
3. PBS Online (1997). *Real-life stories*. Available at <http://www.thirteen.org/bid/>.
4. Pearlman, R. (1998). *Advance care planning: Ethical topics in medicine*. Available at University of Washington School of Medicine Ethics in Medicine Web site: <http://eduserv.hscer.washington.edu/bioethics/topics/adcare.html>.

Resources

Advanced Care Planning Resources

Articles

(2001). Thinking ahead: Advance planning for end-of-life care. Available for download at <http://www.lastacts.org/files/misc/THINKINGAHEAD.pdf>.

(2001). State initiatives in end-of-life care. Focus: Advance care planning--Part 1. Approaches for patients from marginalized groups: Twelfth in a series of briefs profiling promising new policies and practices throughout the country in end-of-life care. To order call 816-842-7110, or available for download at <http://www.lastacts.org/files/publications/unbefriended-final.pdf>.

Baker, M. (2002). Economic, political and ethnic influences on end-of-life decision-making: A decade in review. *J Health Soc Policy* 14(3): 27-39. [PubMed Abstract](#).

Blackhall, L., Frank, G., Murphy, S., Michel, V., Palmer, J. & Azen, S. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine* 48(12): 1779-1789. [PubMed Abstract](#).

Briggs, L. (2003). Shifting the focus of advance care planning: Using an in-depth interview to build and strengthen relationships. *Innovations in End-of-Life Care* 5(2) www2.edc.org/lastacts.

Caralis, P., Davis, B., Wright, K. & Marcia, E. (1993). The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *Journal of Clinical Ethics* 4(2): 155-65. [PubMed Abstract](#).

Cooper, J., Weber, J., Evans, P. & Juozapavicius, K. (2001). End-of-life decisions: physicians as advocates for advance directives. *J Am Osteopath Assoc* 101(10): 571-5. [PubMed Abstract](#).

Curtis, J. (2000). Communicating with patients and their families about advance care planning and end-of-life care. *Resp Care* 45(11): 1385-94. [PubMed Abstract](#).

Dupree, C. (2000). The attitudes of black Americans toward advance directives. *J Transcultural Nurs* 11(1): 12-18. [PubMed Abstract](#).

Ebell, M. (1994). Practical guidelines for do-not-resuscitate orders. *American Family Physician* 50(6): 1293-9, 1303-4. [PubMed Abstract](#).

Ersek, M., Kagawa-Singer, M., Barnes, D., Blackhall, L. & Koenig, B. (1998). Multicultural considerations in the use of advanced directive. *Onc Nurs Forum* 25(10): 1683-89. [PubMed Abstract](#).

Fischer, C., Atkins, K., Cedeno, S. & Sears, M. (1996). Advance directives: Discussion of death and dying issues between physicians and their HIV positive patients in medically underserved communities in New York City. *Meeting Abstract, Int Conf AIDS* 11(2): 431.

Hines, S, Glover, J., Babrow, A., Holley, J., Badzek, L. & Moss, A. (2001). Improving advance care planning by accommodating family preferences. *J Palliat Med* 4(4): 481-9. [PubMed Abstract](#).

Ho, V., Thiel, E., Rubin, H. & Singer, P. (2000). The effect of advance care planning on completion of advance directives and patient satisfaction in people with HIV/AIDS. *AIDS Care* 12(1): 97-108. [PubMed Abstract](#).

Kelly, C. (1999). Tips on talking to your patients about advance directives. *ACT-ASIM Observer* Mar 99: Available on their website. www.acponline.org/journals/news/mar99/advdir.htm.

Klessig, J. (1992). The effect of values and culture on life support decisions. *West J Med* 157(3): 316-322. [PubMed Abstract](#).

Lapine, A., Wang-Cheng, R., Goldstein, M., Nooney, A., Lamb, G. & Derse, A. (2001). When cultures clash: Physician, patient, and family wishes in truth disclosure for dying patients. *J Palliat Med* 4(4): 475-80. [PubMed Abstract](#).

Lofmark, R. & Nilstun, T. (1993). Do-not-resuscitate orders--should the patient be informed? *J Int Med* 241(5): 421-5. [PubMed Abstract](#).

Martin, D., Thiel, E. & Singer, P. (1999). A new model of advance care planning: Observations from people with HIV. *Arch Intern Med* 159(1): 86-92. [PubMed Abstract](#).

Molloy, D., Guyatt, G., Russo, R., Goeree, R., O'Brien, B., Bedard, M., Willan, A., Watson, J., Patterson, C., Harrison, C., Standish, T., Strang, D., Darzins, P., Smith, S. & Dubois, S. (2000). Systematic implementation of an advance directive program in nursing homes: A randomized controlled trial. *JAMA* 283(11): 1437-44. [PubMed Abstract](#).

Murphy, S., Azen, S., Frank, G., Michel, V. & Blackhall, L. (1997). Ethnicity and advance care directives. *J Law Med Eth* 24(2): 421-5.

Pearlman, R., Cole, W., Patrick, D., Starks, H. & Cain, K. (1995). Advance care planning: Eliciting patient preferences for life-sustaining treatment. *Patient Education and Counseling* 26: 353-361. [PubMed Abstract](#).

Perkins, H. (1993). Autopsy decisions: The possibility of conflicting cultural attitudes. *J Clin Ethics* 4(2): 145-54. [PubMed Abstract](#).

Perkins, H., Geppert, C., Gonzales, A., Cortez, J. & Hazuda, H. (2002). Cross-cultural similarities and differences in attitudes about advance care planning. *J Gen Intern Med* 17(1): 48-57. [PubMed Abstract](#).

Rotheram-Borus MJ, Lester P, Wang P, and Shen Q (2004). Custody plans among parents living with human immunodeficiency virus infection. *Arch Pediatr Adolesc Med* 158: 327-332. www.archpediatrics.com. [PubMed Abstract](#).

Singer, P., Thiel, E., Salit, I., Flanagan, W. & Naylor, C. (1997). The HIV-specific advanced directive. *J Gen Int Med* 12(12): 729-35. [PubMed Abstract](#).

Teno, J. (2000). Advance directives for nursing home residents: Achieving compassionate, competent, cost-effective care. *JAMA* 283(11): 1481-2. [PubMed Abstract](#).

Teno, J., Fleishman, J., Brock, D. & Mor, V. (1990). The use of formal prior directives among patients with HIV-related diseases. *J Gen Int Med* 5: 490-94. [PubMed Abstract](#).

Tucker, R. (1994). Patient self-determination act: An African American perspective. *Cambridge Qtrly of Healthcare Ethics* 3(3): 417-19. [PubMed Abstract](#).

Voltz, R., Akabayashi, A., Reese, C., Ohi, G. & Sass, H. (1998). End-of-life decisions and advance directives in palliative care: A cross-cultural survey of patients and health care professionals. *Journal of Pain and Symptom Management* 16(3): 153-162. [PubMed Abstract](#).

Waters, C. (2000). End-of-life care directives among African Americans: Lessons learned - A need for community-centered discussion and education. *J Community Health Nurs* 17(1): 25-37. [PubMed Abstract](#).

Waters, C. (2001). Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. *Qual Health Res* 11(3): 385-98. [PubMed Abstract](#).

Books

Akabayashi, A. & Voltz, R. (2001). Advance directives in different cultures. In: Bruera, E. & Portenoy, R., (Eds.). *Topics in palliative care, volume 5*. New York, NY: Oxford University Press.

Beckett, A. (1998). End-of-life decisions: A psycho social perspective. In: Steinberg, M. & Younger, S., (Eds.). *End-of-life decisions in AIDS*. Washington, DC: American Psychiatric Press, Inc.

Haeckler, C., Moseley, R. & Vawter, D. (1989). *Advance directives in medicine: Legal, ethical and medical considerations*. New York: Praeger Press.

Kaufert, J., O'Neil, J. & Koolage, W. (1991). The cultural and political context of informed consent for Native Canadians. In: Postl, B., Gilbert, P., Goodwill, J., et al., (Eds.). *Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health, Whitehorse, Yukon, May 20-25, 1990*. Winnipeg, Manitoba: University of Manitoba Press.

Midwest Bioethics Center (1999). *Caring conversations - Making your wishes known for end-of-life care*. A workbook designed to assist patients and families share meaningful conversation while making practical preparations for end-of-life decisions. Available to download free online or call (816) 221-1100 to order.. www.midbio.org/workbook.pdf.

Pearlman, R., Starks, H., Cain, K., Cole, W. & Rosengren, D. *Your life, your choices*. A workbook designed to assist patients and families with developing advance directives. www.hsrdr.research.va.gov/publications/your_life/.

Videos

Supportive Care of the Dying

www2.edc.org/lastacts/archives/archivesMarch03/resources.asp.

Person to Person: Discovering Patient Wishes in Planning for End of Life - A Tool for Physicians.

Websites

Bioethics - eduserv.hscer.washington.edu/bioethics. The University of Washington School of Medicine bioethics website has discussion, case examples, and resource information on ethical issues in Advance Care Planning.

NOLO - www.nolo.com. A comprehensive, easy to understand resource center for legal issues. Useful information in Wills and Estate Planning, Health Care Directives, and Power of Attorney including encyclopedia articles, FAQs, and a Q&A section.

US Living Will Registry - www.uslivingwillregistry.com. Allows electronic storage of patient advance directives, available to health care professionals 24 hours a day by phone or via the internet. They also provide advance directive storage services for health care professionals and hospitals. Information available in English and Spanish.

WA: Aging and Adult Services Administration - www.AASA.DSHS.wa.gov. The website for Washington's DSHS Aging & Adult Services Administration. It contains FAQs on Advance Directives as well as sample forms for Washington State.

WA: Northwest Justice Project - www.nwjustice.org. The Northwest Justice Project has FAQs and downloadable Advance Directives for Washington State. It also has Spanish and Russian translations of both the information and the forms, as well as a list of their statewide offices.

WA: Volunteer Attorneys for People with AIDS (VAPWA) - www.kcba.org/VAPWA/vapwa.htm. Volunteer Attorneys for People with AIDS provides legal information and assistance to low-income PWAs. Its website has online information about Advance Directives, including downloadable forms. It also has a list of legal resources throughout Washington State.

Permanency Planning Resources

Articles

Draimin, B., Gamble, I., Shire A. & Hudis, J. (1998). Improving permanency planning in families with HIV disease. *Child Welfare* 77(2): 180-194. [PubMed Abstract](#).

Levine, C. (1995). Orphans of the HIV epidemic: Unmet needs in six U.S. cities. *AIDS Care* 7(Supp 1): S57-S62. [PubMed Abstract](#).

Mason, S. (1998). Custody planning with HIV-affected families: Considerations for child welfare workers. *Child Welfare* 77(2): 161-177. [PubMed Abstract](#).

Merkel-Holguin, L. (1998). Permanency Planning for HIV-affected families. *Protecting Children* 13(4): 14-15.

Wilfert, C., Aronson, J., Beck, D., Fleischman, A., Kline, M., Mofenson, L., et al. (1999). Planning for children whose parents are dying of HIV/AIDS. American Academy of Pediatrics. Committee on Pediatric AIDS, 1998-99. *Pediatrics* 103(2): 509-511. [PubMed Abstract](#).

Videos

Family Center

www.thefamilycenter.org.

A gift for my children. A 20-minute video produced by The Family Center that illustrates issues confronted by families as they try to create custody plans for their children. "This video is designed for professionals to use with families and as a training tool for professionals." It can be

ordered from their website. They also have brochures in English and Spanish on permanency planning issues that can be ordered free of charge.

Websites

Brooklyn Legal Services Corp. & Gay Men's Health Crisis -

www.bronxlegalservices.org/ProSeTopics/Aids_topics.htm. *Facing the future: a legal handbook for parents with HIV disease*. New York, NY. This booklet can be ordered from South Brooklyn Legal Services at (718) 237-5546 or from their website.

Child Welfare League of America - www.cwla.org/programs/hiv aids. *HIV permanency planning news*. Available on their website.

Family Ties Project - www.familytiesproject.org. *Facing the future: An introduction to life planning for parents and caregivers*. Washington, D.C.: Consortium for Child Welfare. This booklet outlines the various legal options for permanency planning. Some sections are specific to the District of Columbia, but there is a lot of good, readable general information. It can be downloaded from their website.

National Abandoned Infants Assistance Resource Center - socrates.berkeley.edu/~aiarc. Legal permanency planning for HIV-affected families. The entire issue of *The Source*, 5(2), is devoted to HIV permanency planning and can be downloaded from the AIA's website.