

ADVANCE CARE PLANNING EXERCISE

It is helpful to be able to say to patients and families that you have done your own advance care planning as a matter of routine care. It is also helpful to have experienced the process of trying to imagine being in states of serious illness and mental incapacity.

You may be interested in using the following exercise in a group educational setting. This exercise provides a way for health care professionals to consider their feelings and responses to their own advance care planning.

First Scenario

We will start by considering a scenario in which you have an advanced illness with a very poor prognosis (less than 3 months if the disease follows its usual course). You are in the hospital in a coma with a poor likelihood of recovery when you develop a small bowel obstruction.

First, consider what you would want to be the *goals* of your care in this circumstance. Would you want: (a) all possible intervention to prolong life, (b) full intervention, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want major surgery? [*Pause briefly.*] How about an intermediate option with a nasogastric tube, and no intake by mouth? [*Pause briefly.*] How about only intravenous antibiotics? [*Pause briefly.*] What about only comfort measures with analgesics and sedatives?

Let's look at what goals you selected. How many of you selected all possible interventions to prolong life? [*You may want to list this on the left-hand side of a flip chart or overhead projector. Count hands and record the number.*] How many selected full interventions, but with early reassessment? [*Count hands and record the number.*] How many chose interventions that might help but are not too invasive? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Let's look at what treatment options you selected. How many wanted major surgery? [*Count hands and record the number on the right-hand side of the flip chart or overhead projector opposite the corresponding goal.*] How many wanted intermediate interventions with an NG tube? [*Count hands and record the number.*] How many wanted antibiotics? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Notice how many of you declined all interventions and wanted only comfort measures. Some of you wanted some noninvasive or minimally invasive measures. Also, notice the inconsistencies. When faced with specific choices, some of you changed to a different "level" as related to overall goals. If we were to move to a scenario of rosier prognosis, we would still be likely to find a range of choices within the group. Many of you would change your choices.

This process leads to an opportunity to think about your own internal inconsistencies, how you might value various options, and how you would set limits. Further, it helps you to be specific about your relationship to death and dying.

Many of the questions in your mind are questions that patients will have. Many are those that only people with advanced education ask. In fact, lawyers and physicians tend to be either the fastest or the slowest to complete these types of exercises. Most people, regardless of educational experience, find these exercises helpful and doable.

Second Scenario

Now, consider a scenario in which you have a mild chronic condition. It affects your day-to-day living to a modest degree. You now contract a life-threatening but potentially reversible condition such as *Staphylococcus aureus pneumonia*. You are barely conscious and cannot make decisions for yourself. Let's go through the same exercise. First, let's discuss goals. Would you want: (a) all possible intervention to prolong life, (b) intervention, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want care in an intensive care unit, including pressors and intubation? *[Pause briefly.]* Would you want a more intermediate intervention, such as multiple intravenous antibiotics and low-dose pressors but no transfer to an intensive care unit and no intubation? *[Pause briefly.]*

Now consider a barely invasive intervention — would you want IV antibiotics but a limit on the degree of laboratory testing? *[Pause briefly.]* Would you want only comfort care with analgesics and sedatives? *[Pause briefly.]*

Let's look at what you selected now. How many of you selected all possible interventions to prolong life? *[You may want to list this on a flip chart or overhead projector on the left hand side, as before. Count hands and record the number.]* How many selected intervention, but with early reassessment? *[Count hands and record the number.]* How many chose interventions that might help but not too invasive? *[Count hands and record the number.]* How many chose non-invasive comfort care only? *[Count hands and record the number.]*

Let's look at what treatment options you selected. How many chose all measures to prolong life? *[Count hands and record the number on the right-hand side of the flip chart or overhead projector opposite the corresponding goal.]* How many wanted intermediate interventions with IV antibiotics, but no ICU care? *[Count hands and record the number.]* How many wanted only IV antibiotics? *[Count hands and record the number.]* How many chose noninvasive comfort care only? *[Count hands and record the number.]*

Notice the changes. Most of you wanted interventions that were much more "aggressive". Contrast your answers to this scenario with the first. Do you have a sense of where your threshold for intervention lies relative to prognosis and disability? Some of you could now move to other scenarios and treatments that would more clearly define your personal threshold for intervention. For many people, it is enough to define where the threshold is, without resolved detailed decisions at the threshold. Often this is where physician recommendation plays a stronger role and proxy discretion comes in. Many patients are content with this.

Notice how most of you selected intervention choices that were consistent with your general goal. This is usually the case. However, some of you chose treatments that didn't quite correspond with the overall goal. Research shows that trying to predict intervention choices from stated general goals (such as those in a living will) is weaker than extrapolating from specific preferences. While identifying goals provides a reality check and organizes our thinking, this is not a substitute for considering specific examples.

Most people, after weighing other scenarios and having fully completed an advance care planning worksheet, will feel that their views are well articulated. Some proportion of patients, however, will feel that there is something more that needs to be said. Invite them to give you a statement in their own words, such as in a letter. Ask them to consider other matters, such as whether the patient wants to die at home, or whether autopsy and/or organ donation is desired. Invite the formal proxy to be designated. If more than one proxy is desired, invite the patient to give some sense of order of authority in cases of disagreement.

National Cancer Institute grant (R25 CA76449) to Sara J. Knight, Ph.D., at the Robert H. Lurie Comprehensive Cancer Center provided the funding for the development of this program. This material was adapted from the EPEC project (Education for Physicians on End-of-life Care).