NEW SIDEBAR TAB

*SUGGESTIONS FOR GROUP PRESENTATIONS OF 6-STEPS*

 *6-Steps* was designed to be presented by facilitators, either in individual or group consultations. During community trials, it was used in groups with as many as 30 participants. Depending on group size, these groups take 1 ½ to 2 ½ hours. In these trials, more than 85% of the participants completed all three parts of their Living Wills with signatures witnessed by others in the group. When these groups were conducted in a hospital, in this case Swedish/Edmonds Hospital, most of the completed documents were immediately scanned into participants’ electronic records. The next phase of the development will involve training medical assistants and others in facilitating *6-Steps* completion by patients receiving chemotherapy and dialysis.

 Below are suggestions for training facilitators to present *6-Steps* in groups. The material in the “Guide” tab of this site is also useful for this purpose.

General Guidelines

Even if you have created a living will in another form, it is strongly recommended that you complete *6-Steps* because it is much more comprehensive than other advance care planning documents*.* As you complete it, make note of anything that gives you pause. These are the areas in which you may want to take particular care during your presentation.

 This is not a script: it is a list of points that should be made during group presentations of *6-Steps*.

1. Add “color” by telling interesting examples that illustrate the points and ask participants to share their experience when relevant. This is very important because end-of-life decision-making is more driven by emotion than fact. (It must be that way because the facts cannot be known in advance.)
2. Don’t hesitate to use tasteful humor to relieve emotional tension.
3. Accurately paraphrase the content but read the crucial items that must be signed in the formal documents.
4. Do not reveal your own advance directive preferences. It is essential that we do nothing to influence participants’ decisions beyond providing factual information and helping them clarify (not change!) their beliefs and values.
5. As stated below, despite the fact that most people are unsure and ambivalent about what they would want, one never knows when a health crisis will occur. Therefore everyone should have completed documents in effect. The documents can be changed at will if participants later change their minds. Therefore the goal of the presentation is to have every participant leave with a completed valid living will.

Introduction

1. Introduce yourself, including what motivated you to want to help others complete living wills.
2. Ask participants to sign a consent form if your setting requires one
3. Ask about participants’ experience with serious illness and/or death in relatives or friends—trying to tactfully interrupt overly long accounts.
4. Ask who has an AD.
5. Explain that everyone has an AD—because full treatment is mandated by first responders and hospital patients who lack explicit instructions to the contrary.
6. State the purpose of the meeting today is for everyone to complete a three-part Living Will. Everyone will receive a second copy of 6-Steps can be used at home and in response to second thoughts about any decisions made today.
7. Ask participants to turn to the 6-Steps introduction and discuss each of the 6 questions in greater detail.
8. Points to be made about treatment options:
9. Aggressive treatments
10. Can cure curable illnesses (which are rare in patients with terminal conditions) or slow the progression of others
11. Attempt to use palliative care measures to control pain and discomfort but often involve2 procedures that cause both.
12. Often involve intervention that is invasive and can be costly
13. Differentiate between treatments that prolong life and those that would allow life to end naturally (e.g. CPR—cardiopulmonary resuscitation-- vs DNR –do not resuscitate—or the more positive AND –allow natural death) and discuss the possible positive and adverse effects of each.
14. On the positive side, CPR and electronic stimulation can restore a heartbeat. If the heart stopped beating in response to an event like shock following a bee sting, CPR is a valuable life-restoring procedure.
15. But on the negative side, CPR in real life is not the way it look on TV. If begun too late it can restart the heart after the brain has lost many of its capacities

 Other measures also have positive and negative effects, eg feeding tubes

 can provide necessary nutrition but may require 4-point restraints and can

 flood the body with nutrients it cant use.

1. Limited treatments
2. Treats the illness as manageable, but not curable.
3. Therefore its interventions are more modest.
4. Often involves palliative care (that may include CPR)
5. Comfort care only
6. Treats the illness as incurable but the symptoms as manageable
7. A variety of interventions seek to make the patient more comfortable.
8. It often includes hospice care.
9. It often prolongs life because patients experience less stress and fewer unwanted direct effects of interventions.
10. Stress that there is not one right way to approach death and that the choice is made on the basis of combining knowledge about one’s health condition and its prognosis with personal values that shape and give meaning to the roadmap that people chart for themselves.
11. In medicine there are few certainties, therefore many possibilities
12. But much of what is possible is not probable.
13. The core value issue is:
14. how much physical, emotional, and economic hardship is one willing to endure to prolong one’s life?:
15. in other words, which do you value more: length of life or quality of life?

10. Point out three of the main costs of putting off these difficult decisions:

a. You may not receive the full treatment that you want or you have to undergo prolonged, painful, expensive, invasive treatments that you hoped to avoid;

b. You force loved ones to make decisions for you without knowing exactly what you want, exposing them to the risk of a lifetime of guilt about having let you go much sooner than you wanted, or kept you uncomfortably alive much longer than you wanted.

c. If you don’t take responsibility for making critical decisions, family members and friends may have life-long conflict if they disagree about which type of care you would have chosen.

That’s why it is essential to make these decisions now.

11. When answering question 5, differentiate between:

a. living wills, that are often created before a serious illness develops and are signed by patients; and

b. POLST forms, that are not created until a serious illness develops and must be signed by a doctor.

Step 1

1. Introduce Step 1 by defining “values” as a deeply personal important standards of personal behavior. They are influenced by culture and religion, family beliefs, life experience, and they change over time in response to new knowledge and experience.

1. They are subjective and neither right nor wrong…
2. but they do have objective, real world consequences that may or may not be desirable.
3. Values are emotional, and often trump knowledge, that is cognitive,
4. Articulating your values helps you refine them by deciding which to keep, change, and/or replace.
5. The questions in Step 1 are a few of the value dimensions that influence e-o-l decisions but they are not in any way the full gamut of options. Step 2 will help you expand your value framework in your own words.
6. Now guide participants in the completion of Step 1

2. Help participants summarize their preferences in terms of duration vs. quality of life.

3. Ask 4 different participants to each read and discuss each scenario in Section B. This is the only clear chance for participants to understand the personal impact of the decisions they are about to make.

Step 2

1. Explain that Step 2 is critically important because it communicates core messages about your identity, beliefs, and values to your healthcare providers and significant others.

a. Since the Advance Directive that you will complete in Step 3 covers only a few eventual possibilities, the personal statement fills in the blanks so the type of care that you receive is more likely to be the type of care that you want.

b. The questions listed in *6-Steps* give you some idea about the kinds of information about you that you will want others to have. Bear in mind the three sources of preferences for end-of-life care:

(1) Spiritual/religious

(a) Some believe that by suffering, they absorb the pain of others and/or experience Christ’s agony on the cross.

(b) Some believe that their religion requires them to do everything possible to prolong their lives. HOWEVER

In 2006 the Washington State Catholic Conference stated that hospitals have an obligation to offer extraordinary treatments but individuals are not obligated to accept treatments that are extraordinary for them.

(c) Some believe that death is part of the eternal cycle of life and therefore should be accepted.

(2) Family

(a) Understandably, families do not want to lose the people they love…

(b) particularly when they have “unfinished business”.

(c) Families are also impacted by the cost of the care their loved ones receive, both during active treatment and after their loved one dies

(3) Personal

(a) This is the most important factor in your decision: it is your life and your choice as to how you live until it ends.

(b) Consider your spiritual/religious beliefs and the wishes of your family, but make your own decision rather than doing what you think others want you to do. This is your final act: your last chance to determine the length and/or quality of the end of your life.

c. You may not have time to finish it today but it is very important that you start by writing a few sentences or paragraphs right now.

d. Ask if anyone is willing to read one or two sentences of their personal statement.

Step 3

1. Tell participants that this is where the decisions become challenging. It is important for everyone to understand the meaning of all the terms, some of which may be new to you. Encourage participants to ask for clarification whenever they are uncertain about the meaning of a term.

2. Point out that expressing their preferences is important no matter which type of care they want to receive.

a. Even though full treatment is the default in many institutions, some doctors might in good faith offer less aggressive treatment unless the patient specifically requested full treatment.

b. Limited and comfort only care are likely to be offered only if patients specifically request them.

3. To frame these decisions properly, ask participants to imagine that when their living will comes into play, they don’t feel the way they do today but instead are frail, possibly in pain, unable to eat or drink independently, unable to control their bladder or bowls, and/or unable to communicate coherently.

4. Painstakingly go through each item asking participants to make decisions when indicated and explaining the logic of statements that participants will endorse when they sign the advance directive.

5. Have signatures witnessed by participants who are not hospital employees or volunteers, and not heirs or relatives.

Step 4

1. Describe the function of the health care representative (aka surrogate) as the participants’ voices when they cannot speak for themselves, either because they have lost mental capacity or are unconscious.

2. Referring to *6-Steps*, summarize the qualities of good surrogates.

3. Indicate that spouses may or may not be good decision makers depending on their ability to control their own fears and emotions.

4. If enough participants are accompanied by their surrogates, take 2 minutes to ask the surrogate to describe the kind of e-o-l care he/she thinks the participant has chosen. Use questions in middle of the step to guide this discussion. (If too few to use the group’s time for this purpose, ask the dyads to do this exercise for a few minutes right after the session ends.)

5. Remind the surrogates that when they are acting for the participant they are responsible to:

a. Express the participant’s wishes as stated.

b. Control the impulse to override the participant’s preferences with their own; and

c. Resist any almost efforts by providers to override the participant’s preferences with statements like “If it were my mother, I would…”

Invite one or more surrogates to role play the way they plan to resist such influence attempts.

Step 5

1. Present this step by reminding participants that their living wills will affect the type of e-o-l care only if their doctors will enter orders that are consistent with their wishes. Therefore it is essential that they bring copies of their documents to their doctors and summarize their wishes.

2. This step structures that process and creates an implicit contract in which doctors commit to honoring participants’ wishes.

3. The statement that participants will hold their providers blameless if their wishes are honored is a very important commitment of good faith by the participant.

4. Stress the importance of providing doctors accurate information about how to contact surrogates and back-up representatives.

5. Stress, too, the importance of identifying anyone who participants do not want to have a voice in determining their care.

6. Advise participants to bring a copy of pages 18-19 to every meeting with every provider to make certain that their wishes are known.

7. Discuss the importance of participants’ telling providers their preferred balance of optimism and reality.

8. Involve participants in role plays of the generic and illness-specific discussion of advance directives. Include enactment of doctor advising surrogates to overrule patients’ preferences using various ploys, e.g. “If it were my wife, I would…” or “In your wife’s condition, this is what I would want….”

Step 6

1. Introduce this step as a reminder of things that participants should do to increase the likelihood that their documents will be available when and where they are needed.

2. Remind participants that keeping the documents in their safe-deposit boxes or lawyers’ safe guarantees that honoring their wishes will be delayed, and may never be honored.

Final Points

1. Ask participants to complete the 6-Steps evaluation form, including their contact information if they would like us to contact them with follow-up information.

2. Tell participants that immediately following the session they can have their living wills scanned into their EMRs if they are patients of anyone affiliated with Swedish and therefore already have a chart.