

Appendix A

The Medical Decision-Maker Quiz: A Tool for Better Understanding

Instructions: As health care decision-maker, answer these questions in the way you think the person would answer them. Then ask the person to answer them and compare your answers. Where the answers differ, discuss why that is.

Important: This is not an advance directive. The questions are for discussion only.

1. Circle how much you fear the following near the end of life:

- (1) Very Little (2) Some (3) Very Much
- Being in pain 1 2 3
 - Losing the ability to think 1 2 3
 - Being a financial burden on loved ones 1 2 3
 - Losing control over my medical care 1 2 3
 - Losing ability to practice my faith 1 2 3

2. Is it more *important* for you to:

- Have your wishes followed at the end of life, even if family members or friends disagree, or
- Have family and friends all agree on decisions, even if different from how you would decide, or
- I am uncertain.

3. Here are things about end-of-life care that some people believe. Do you agree?

- If a dying person can't get enough nutrition by mouth, a feeding tube should always be used if it will keep the person alive.
 - Yes, I agree
 - No, I don't agree
 - I don't know
- Once a treatment is started to keep someone alive, it's sometimes okay to decide to stop and withdraw it when the person's quality of life is very low.
 - Yes, I agree
 - No, I don't agree
 - I don't know
- You are very sick, and the doctors cannot stop the disease. With all possible treatments, you might live for another few weeks. During that time, you would be on a breathing machine. You would drift in and out of consciousness. Without these treatments, you would die in a few days. Would you want the breathing machine and other treatments?
 - Yes, I think so
 - No, probably not
 - I don't know

- 4. You have severe Alzheimer’s disease. You can’t get out of bed, and you can’t recognize or talk with your loved ones, but you are not in pain. You could live like this for many months. However, you get recurring infections which are treated with antibiotics. You get another infection, this time pneumonia. If the doctors give you an antibiotic, you will almost certainly recover from the infection. Without the antibiotic, you will die in a few days. Do you want the antibiotic if you can otherwise be kept comfortable?
 - a. Yes, I think so
 - b. No, probably not
 - c. I don’t know

- 5. You have poor circulation, which resulted in one leg being amputated. Now, your other leg develops gangrene and doctors recommend amputation because it could be fatal. You also have moderate dementia causing mental confusion. Would you want the operation?
 - a. Yes
 - b. No
 - c. I am uncertain

- 6. You are in a permanent coma and have a tube inserted in your stomach for food and fluids. Would it be important to you that decisions about your treatment are guided by particular religious beliefs or spiritual values that you hold?
 - a. Yes
 - b. No
 - c. I am uncertain

If so, what are they

- 7. You were terminally ill, but a course of treatment might extend your life by six additional months. Would you want the treatment even though it has severe side effects – pain, nausea, vomiting, and weakness?
 - a. Yes
 - b. No
 - c. I am uncertain