

What's important to me - SDM

Graphic Values History Tool
(Original Version)

Questions for
Substitute Decision Makers

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What are values?

Values are the things that matter to you -- what you feel is important in life.

Values and Medical Decisions

In health care, your wishes for treatment will depend on your values. Some people, for example, value independence, and would not want treatment that prolongs life if they could no longer live independently. Others, who are less concerned about independence, may feel that their ability to communicate with family and friends is most important. Because we all have different values, some people will decide to have a treatment that others refuse.

"What's important to me" asks questions to help you think about your values.

Advance Care Planning

Most people want to make their own health care decisions. Because of illness or injury, many people will unfortunately lose the ability to make these decisions. If this were to happen to you, a substitute decision maker¹ would be asked to make decisions for you.

You can decide what you want now, while you are capable of making decisions, and tell your substitute decision maker (SDM). Telling your substitute decision maker what you do and do not want is a way of extending your control over the health care you will receive in the future. We call this advance care planning.

Advance care planning “is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future care”². Everyone, from healthy people to terminally ill patients, can benefit from advance care planning. The most important part of the process is the discussion with your substitute decision maker. You may also find it helpful to discuss your plans with a trusted health care professional.

You should review your choices every once in a while, and particularly if your health changes, or if you change your mind about what you want done and not done.

¹ **Substitute Decision Maker (SDM)**: someone who makes decisions on your behalf if you become incapable of making them.

² Sudore, RL., Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel. *JPSM*. 2017;53(5):821-832.e1

Values, not Symptoms

"What's important to me" puts the focus on patient values. Many conditions can cause symptoms such as shortness of breath or constipation. What matters to patients is how they feel about the symptom, and what they wish to be done. If you had such a symptom and there was no chance of recovery, would your quality of life be acceptable to you?

Completing this document

This document is the **SDM version**. The SDM version should be completed by the SDM, and patient version completed by the patient. The two versions should be completed at the same time.

If you are completing this document as a substitute decision maker, you will need to **consider each question from the point of view of the patient**. Your goal is to answer the questions as you believe the patient would answer them. When you have both finished completing the document, you should compare your answers and discuss any differences. This process should give you a deeper understanding of the patient's health care wishes.

Please take the time you need to complete this document. You don't have to answer every question, but try to answer as many questions as you can. Some questions appear more than once: this is part of the design.

Comments

It is recommended that you provide comments to throw light on what you mean. What conditions/circumstances.

More than one change

This document asks questions about one health change (or symptom) at a time. Please try to weigh each scenario by itself.

When several changes happen at the same time, or when one change is quickly followed by another change, it can be much more difficult to adjust. If you wish, you can use the comments section to discuss the impact of several changes happening at the same time.

How to use this tool

This tool can be used in a number of ways:

1. To begin advance care planning, as a way for patients to identify the values they wish to guide treatment decisions. It can be used alone, or along with any other statement of treatment wishes (e.g., living will).
2. When the patient has finished advance care planning, to check that his treatment decisions are in keeping with his values.
3. When faced with immediate medical decisions, to help patients and SDMS identify what is important to the patient.
4. To start conversations between patients and substitute decision makers, or between SDMS and doctors / nurses. Health care professionals can use this tool to identify what the patient feels important when making treatment decisions.

Autonomy and the Law

While patient autonomy³ is important, health care professionals cannot be forced to comply with wishes that are illegal.

³ **Autonomy:** the right of a person to make decisions for themselves.

1. Quality of Life - Independence

Definition

Quality of life - The degree of satisfaction, comfort and enjoyment in life; what makes life worth living.

Background

What gives you quality of life is a personal decision. There are no right or wrong answers. For example, one person may say that being unable to walk is "somewhat acceptable" but being unable to understand what others say is "totally unacceptable." Others may find both situations "somewhat unacceptable."

This section looks at the value of independence in **the patient's** quality of life. Consider whether the patient's quality of life would be acceptable if she found herself in the following situations, **with no reasonable chance of improvement.**

Instructions: Circle the most appropriate answer.

a. What would the patient say about her quality of life if she were **unable to walk, could only get around by wheelchair?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

b. What would the patient say about her quality of life if she were **unable to feed herself?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

c. What would the patient say about her quality of life if she were **unable to wash herself?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

d. What would the patient say about her quality of life if she **could not make her own decisions**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

e. What would the patient say about her quality of life if she were **unable to get outside and must spend all day at home**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

f. What would the patient say about her quality of life if she were **unable to return to the place she lived before she got sick**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

g. What would the patient say about her quality of life if she were **confined to bed and/or needing someone to take care of her 24 hours a day?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

h. What would the patient say about her quality of life if she **needed to live permanently in a nursing home?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

i. What would she say about her quality of life if she **needed to live in a hospital?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

j. Would she have other issues or concerns about your independence? **Write the issues here, and rate it.**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

2. Quality of Life – State of Health

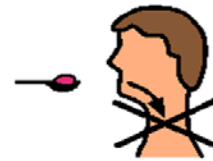
Definition

Quality of life - The degree of satisfaction, comfort and enjoyment in life; what makes life worth living.

This section looks at medical conditions that might change **the patient's** quality of life. Consider whether his quality of life would be acceptable if he found himself in the following situations, **with no reasonable chance of improvement**.

Instructions: Circle the most appropriate answer.

a. What would he say about his quality of life if he was **unable to swallow safely**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

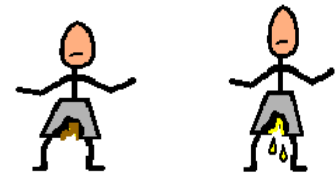
b. What would he say about his quality of life if he was fed by tube into the stomach?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

c. What would he say about his quality of life if he could not control his bowels or bladder (may need to wear adult diapers)?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

d. What would he say about his quality of life if he was blind or deaf?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know
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Comments:

e. What would he say about his quality of life if he **could not understand what others say?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

f. What would he say about his quality of life if he **was often short of breath?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know
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Comments:

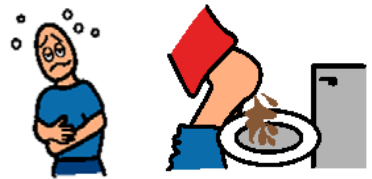
g. What would he say about his quality of life if he **was often thirsty?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

h. What would he say about his quality of life if he **had severe discomfort (such as nausea, diarrhea, and constipation) most of the time?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

i. What would he say about his quality of life if he **had severe untreatable physical pain most of the time?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

j. Would the patient have other concerns about his/her state of health? Write the concern here, and rate it.



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

3. Value trade-offs – (Part 1)

Definition

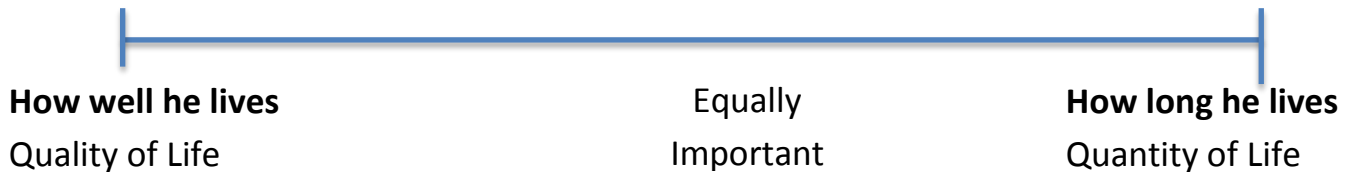
Trade-off - A situation where you must choose between two things of equal value. You may have to lose some of the first thing to gain more of the second thing.

Background

When two important values compete, patients may have to choose one over the other. These choices are personal, and can be difficult to make.

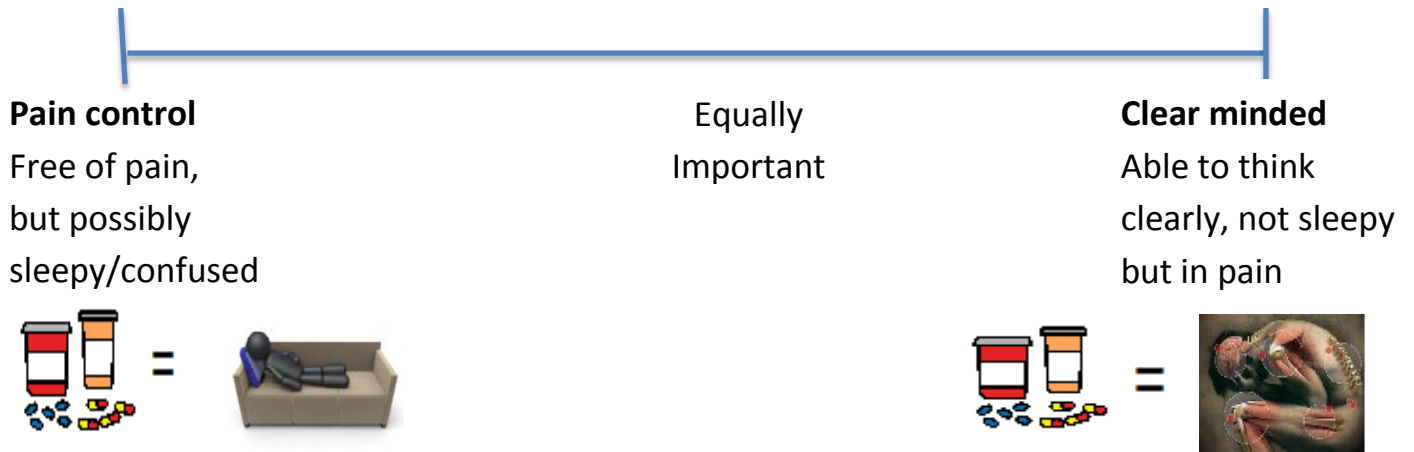
Instructions: Place an "X" on the line to show which value is most important to the patient.

- a. What would the patient say is more important -- **How well he lives** or **how long he lives**?



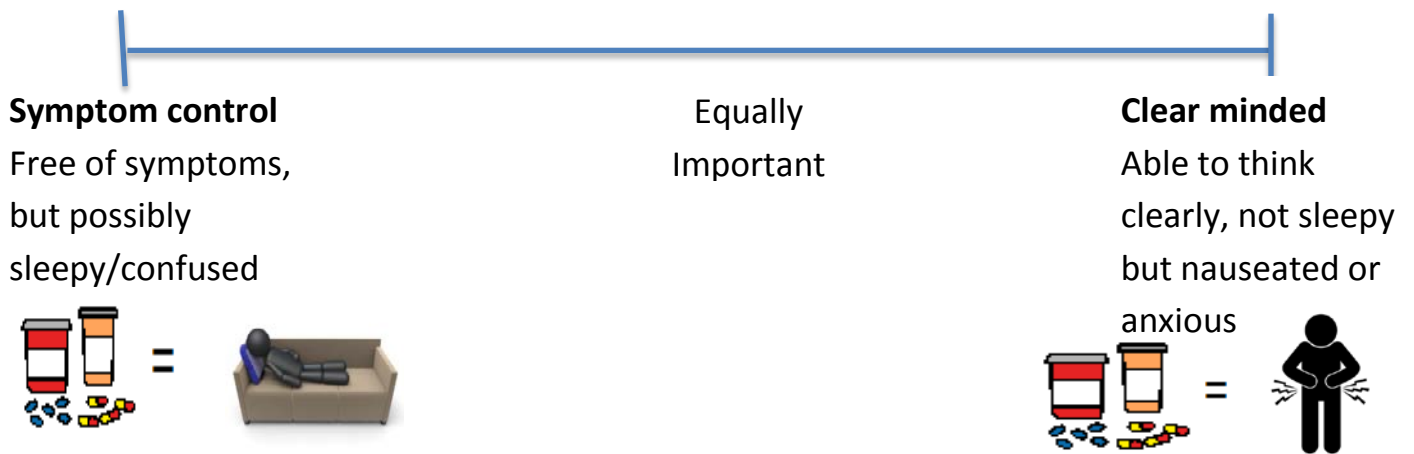
Comments:

b. What would the patient say is more important – **pain control** or **remaining clear minded**?



Comments:

c. What would the patient say is more important – **symptom control** (nausea, anxiety) or **remaining clear minded**?



Comments:

4 Value trade-offs (Part 2)⁴

Definition

Trade-off - A situation where you must choose between two things of equal value. You may have to lose some of the first thing to gain more of the second thing.

Background

When two important values compete, patients may have to choose one over the other. These choices are personal, and can be difficult to make.

Instructions: Circle the most appropriate answer.

- a. What would the patient say if she **needed assistance with basic physical care** (e.g., toileting, washing, feeding), **but was able to think clearly and communicate with her family?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

⁴ Adapted from Scheunemann LP, Arnold RM, White DB. The facilitated values history: helping surrogates make authentic decisions for incapacitated patients with advanced illness. *Am J Respir Crit Care Med* 186(6): 15 Sept 2012.

b. What would the patient say if she **could not make decisions for herself or look after herself**, but she **could recognize family**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

c. What would the patient say if she was **awake** but **could not recognize her family**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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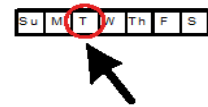
Comments:

d. What would the patient say if she **was not awake** (in a coma)?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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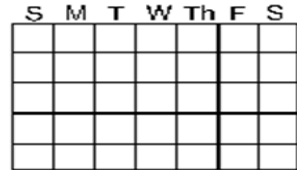
e. Would the patient say it was worth going through **invasive**¹ treatment to live **one more day**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

f. Would the patient say it was worth going through **invasive**¹ treatment to live **one more month**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

1. Invasive - treatment that puts something into the body or cuts into the body.

5. Are some conditions worse than death?

Many treatments keep people alive even if there is **no reasonable chance that the treatment will reverse or improve their condition.**

This section looks at some of these situations. In each situation, ask: would the patient consider this worse than death? How acceptable would the patient find his life if treatment would **NOT reverse or improve his condition?**

Instructions: Circle the most appropriate answer.

a. What if the patient was **often short of breath?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

b. What if the patient was **often thirsty?**



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

c. What if the patient had **severe discomfort** (such as nausea, diarrhea, constipation) **most of the time**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

d. What if the patient **could not communicate his thoughts**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

e. What if the patient could **not recognize family or friends**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

f. What if the patient **needed a feeding tube** to stay alive? (Food and fluid are provided by a tube into the stomach. The patient no longer tastes food.)



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

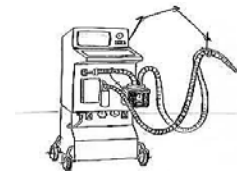
g. What if the patient **needed dialysis**? (The patient is connected to a machine 4 - 6 hours per treatment, 3 treatments per week. Treatments clean his blood and remove fluid.)



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments

h. What if the patient **needed to be connected to a machine 24 hrs a day in order to breathe**? (The machine blows oxygen into the lungs through a tube in the mouth or throat.)



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

i. What if the patient **needed to live in Critical Care Unit for the rest of his life** (only place care can be provided)?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

j. What if the patient had **severe untreatable physical pain most of the time**?



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

k. What other condition would the patient consider **worse than death**?
Write the condition here, and rate it.



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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Comments:

l. What other condition would the patient consider **worse than death**?
Write the condition here, and rate it.



Totally unacceptable 1	Somewhat unacceptable 2	Neutral 3	Somewhat acceptable 4	Totally acceptable 5	Unsure/ don't know 6
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6. How does the patient weigh her chances of survival?⁵

People look at the pros and cons of medical treatments in very personal ways, which is why some people may choose a treatment that others refuse. All treatments carry risks. No one can predict the outcome in every case.

How much would the patient be willing to endure if treatment was likely to save her life, but also likely to leave her in poorer health?

Imagine: The patient is seriously ill. Doctors recommend treatment that has harsh side effects, such as severe pain, nausea, vomiting, or weakness that could last for months. Refusal of treatment will result in death. Treatment may allow her to recover from this illness, **but her overall condition will probably be somewhat worse than before she became ill.**

Instructions: Circle the most appropriate answer for each situation.

Question: Would the patient be willing to endure these side effects if the chance that she recovered was:

a. **High:** over 80% chance she would survive (with somewhat poorer health than before)



Definitely not 1	Probably not 2	Uncertain 3	Probably would 4	Definitely would 5	Unsure/ don't know
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Comments:

⁵ Adapted from American Bar Association Commission on Law and Aging. Consumer's Tool Kit for Health Care Advance Planning: Tool #2. Are some conditions worse than death? Second edition, 2005

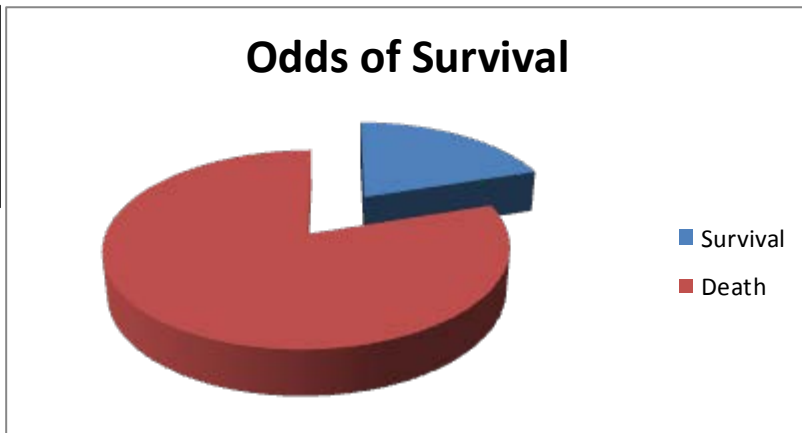
b. **Moderate:** 50% chance she would survive (with somewhat poorer health than before)



Definitely not 1	Probably not 2	Uncertain 3	Probably would 4	Definitely would 5	Unsure/ don't know
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Comments:

c. **Low:** 20% chance she would survive (with somewhat poorer health than before)



Definitely not 1	Probably not 2	Uncertain 3	Probably would 4	Definitely would 5	Unsure/ don't know
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Comments:

d. **Very, very low:** Less than 1 in 1000 or 0.1% chance she would survive (with somewhat poorer health)



Definitely not 1	Probably not 2	Uncertain 3	Probably would 4	Definitely would 5	Unsure/ don't know
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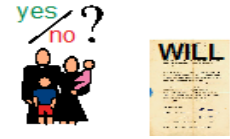
Comments:

7. Impact of Decision on Others

Relationships with family and friends are important to most of us, and our decisions may impact others (financially, physically, emotionally).

Instructions: Circle the most appropriate answer.

a. Do you think your family and friends will support you in **carrying out** the patient's wishes?



Totally unsupportive 1	Somewhat unsupportive 2	Neutral 3	Somewhat supportive 4	Totally supportive 5	Unsure	Undecided
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Comments:

b. Do you think the patient is concerned that he may be a **burden**?



Greatly concerned 1	Concerned 2	Neutral 3	Not concerned 4	Not at all concerned 5	Unsure	Undecided
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Comments:

c. Do you think the patient has other concerns regarding his impact on others?
Write the concern here, and rate it.



Concern:

Greatly concerned 1	Concerned 2	Neutral 3	Not concerned 4	Not at all concerned 5	Unsure	Undecided
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Comments:

8. Religious / Spiritual / Cultural Beliefs

Religious, spiritual, and cultural beliefs play an important role in end-of-life decision making for some people. For others, these beliefs are not important at this time.

Instructions: Please circle the most appropriate answer.

a. How important are the patient's **religious / spiritual** beliefs when making medical decisions?



Not important 1	Of little importance 2	Neutral 3	Important 4	Very important 5	Unsure	Undecided
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Please describe beliefs the patient wishes to have respected.

b. How important is the patient's **culture** when making medical decisions?



Not important 1	Of little importance 2	Neutral 3	Important 4	Very important 5	Unsure	Undecided
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Please describe **cultural practices** the patient wishes to have respected.

c. What most concerns, scares or worries the patient is:

d. Describe any other values or beliefs of the patient regarding medical care:

Statement:

This document represents the patient's values. As a substitute decision-maker, I will use the patient's values when making decisions about her health care.

Date: _____

Signature: _____

Witness #1 _____

Witness #2 _____