

What's important to me - Patient

Graphic Values History Tool
(Original Version)

Questions for Patients

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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 the document

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

When you have both finished completing the document, you should compare your answers and discuss any differences. This process should help you develop a deeper understanding of your health care wishes.

Please take the time you need to complete this document. Every comment you make gives valuable information to your substitute decision maker, and will help guide the discussion that follows. 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

After each question there is space for comments, a place for you to throw light on what you mean. You can give an example of what you were thinking when you gave the rating. When would something be OK and when not? This will help your SDM when he/she has to make decisions for you.

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 of identifying the values you 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 you've finished advance care planning, to check that your treatment decisions are in keeping with your values.
3. When you are faced with immediate medical decisions, the document can help you focus on what is important to you.
4. To start conversations between you and your substitute decision maker, or between you and your doctors and nurses. Health care professionals can use this tool to spell out what you feel important as you or your SDM make 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 to the questions that follow. For example, one person may say "being unable to walk, could only get around by wheelchair" is "somewhat acceptable" but "to be unable to understand what others say" is "totally unacceptable." Others may find both "somewhat unacceptable."

This section looks at the value of independence in **YOUR** quality of life. Consider whether your quality of life would be acceptable if you found yourself in the following circumstances, **with no reasonable chance of improvement.**

Instructions: Circle the most appropriate answer.

a. What would I say about my quality of life if I 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 I say about my quality of life if I were **unable to feed myself?**



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 I say about my quality of life if I were **unable to wash myself?**



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 I say about my quality of life if I **could not make my 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 I say about my quality of life if I 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 I say about my quality of life if I were **unable to return to the place I lived before I 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 I say about my quality of life if I were **confined to bed and/or needing someone to take care of me 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 I say about my quality of life if I **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 I say about my quality of life if I **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. Do you have other concerns about your independence? **Write your 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:

2. Quality of Life – State of Health

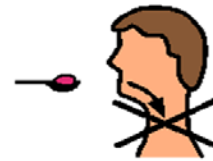
Definition

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 **YOUR** quality of life. Consider whether your quality of life would be acceptable if you found yourself in the following circumstance, **with no reasonable chance of improvement**.

Instructions: Circle the most appropriate answer.

a. What would I say about my quality of life if I were **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:

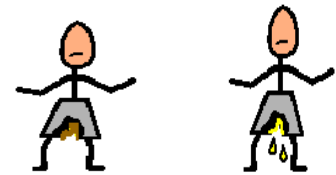
b. What would I say about my quality of life if I were **fed by tube into the stomach?** (Food and fluid are provided by a tube into the stomach. I do not taste foods.)



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 I say about my quality of life if I **could not control my bowels or bladder** (may need to wear adult briefs/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 I say about my quality of life if I were **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 I say about my quality of life if I **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 I say about my quality of life if I **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:

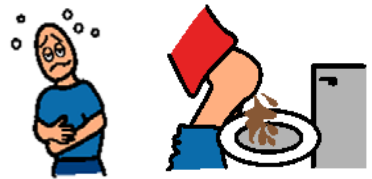
g. What would I say about my quality of life if I **was often thirsty?**



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 I say about my quality of life if I 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 I say about my quality of life if I 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. Do you have other concerns about your state of health? **Write your 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

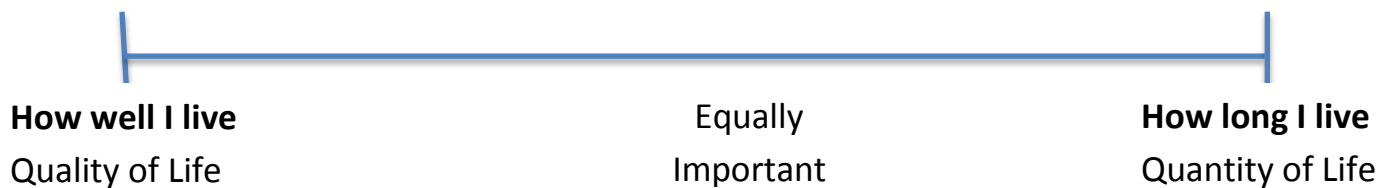
Trade-off - A situation where you must choose between two things of equal value. You may have to lose some of the first thing to gain more of the second thing.

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.

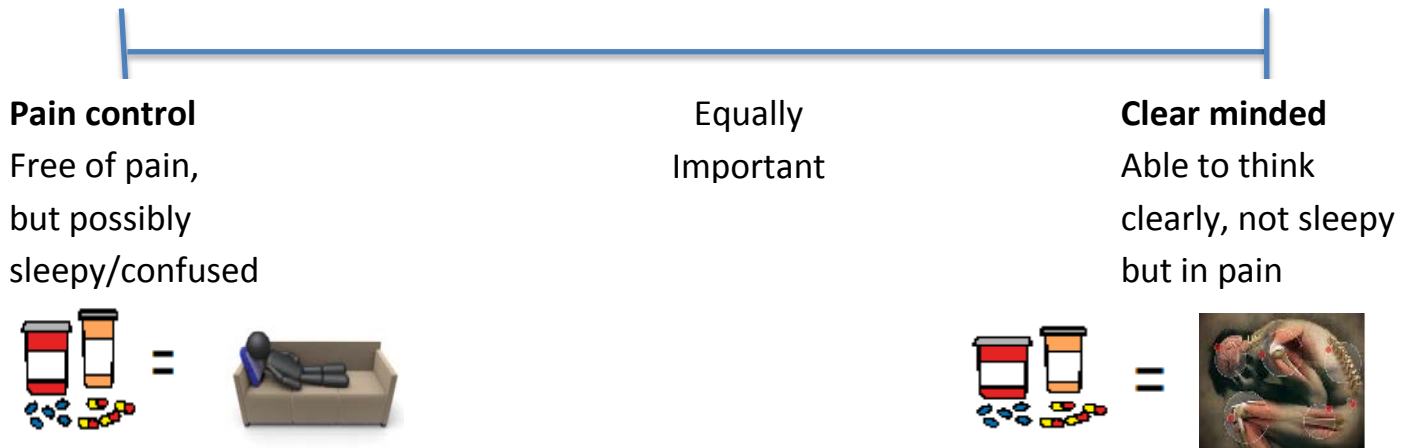
Instructions: Place an "X" on the line to show which value is most important to you.

a. What would I say is more important -- **How well I live** or **how long I live**?



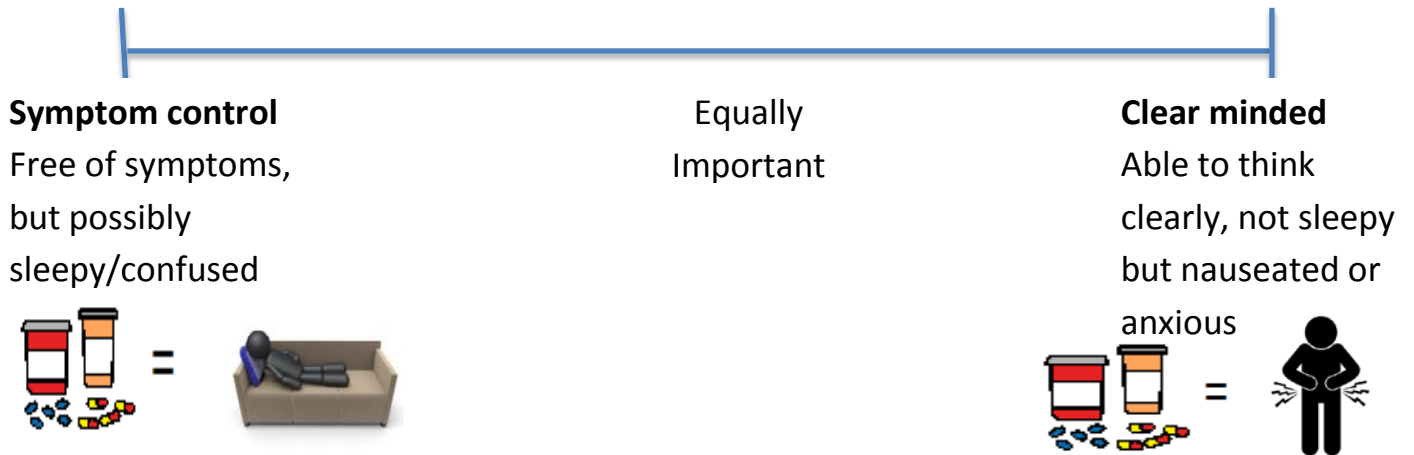
Comments:

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



Comments:

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



Comments:

4 Value trade-offs (Part 2)⁴

Definition

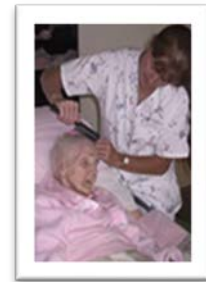
Trade-off - A situation where you must choose between two things of equal value. You may have to lose some of the first thing to gain more of the second thing.

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 I say if I **needed assistance with basic physical care** (e.g., toileting, washing, feeding), **but was able to think clearly and communicate with my 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 I say if I **could not make decisions for myself or look after myself, but I 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 I say if I **was awake but could not recognize my family?**



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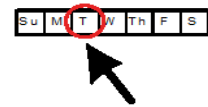
Comments:

d. What would I say if I **was not awake** (e.g., 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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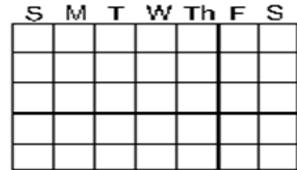
e. Would I say it was worth going through **invasive**¹ treatment to live **one more day**?



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 I 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 yourself: would this be worse than death? How acceptable would I find my life if treatment would **NOT reverse or improve my condition?**

Instructions: Circle the most appropriate answer.

a. What if I 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 I 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 I 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 I **could not communicate my 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 I **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 I **needed a feeding tube to stay alive?** (Food and fluid are provided by a tube into the stomach. I do not taste foods.)



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

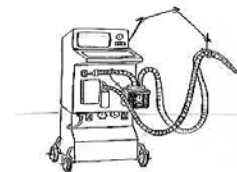
g. What if I **needed dialysis?** (I'm connected to a machine 4 - 6 hours per treatment, 3 treatments per week. Treatments clean my blood and remove fluid.)



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 I **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 I **needed to live in a Critical Care Unit for the rest of my 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 I 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 you consider **worse than death**?
Write 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 you consider **worse than death**?
Write 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 do I weigh my 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 you be willing to endure if treatment was likely to save your life, but also likely to leave you in poorer health?

Imagine: You are 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 you to recover from this illness, **but your overall condition will probably be somewhat worse than before you became ill.**

Instructions: Circle the most appropriate answer for each situation.

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

<p>a. Would I be willing to endure these side effects if the chances that I recovered was High: over 80% chance I would survive (with somewhat poorer health than before I got sick)</p>	<h3>Odds of survival</h3>
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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 Health Care Advance Planning: Tool #2. Are some conditions worse than death? Second edition, 2005

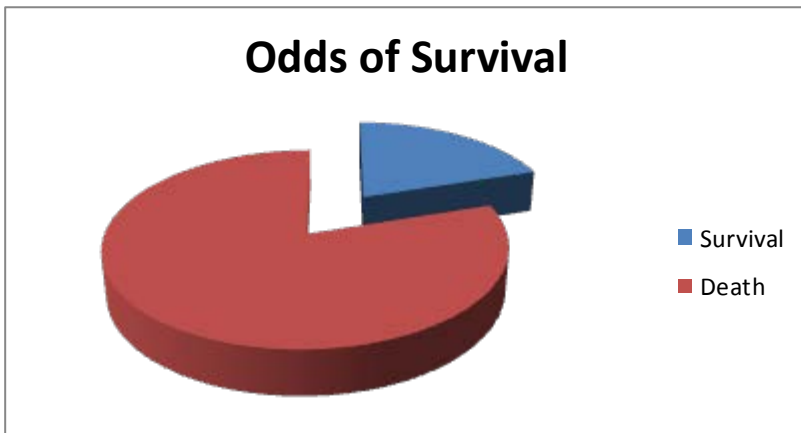
b. Would I be willing to endure these side effects if the chances that I recovered was **Moderate**: 50% chance I would survive (with somewhat poorer health than before I got sick)



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

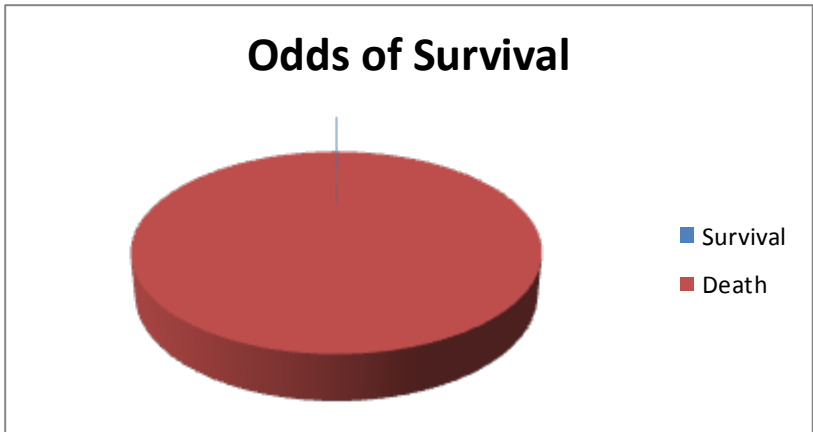
c. Would I be willing to endure these side effects if the chances that I recovered was **Low**: 20% chance I would survive (with somewhat poorer health than before I got sick)



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

d. Would I be willing to endure these side effects if the chances that I recovered was **Very, very low**: Less than 1 in 1000 or 0.1% chance I would survive (with somewhat poorer health than before I got sick)



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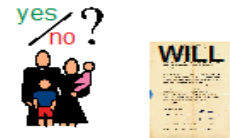
Comments:

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** your wishes?



Totally unresponsive 1	Somewhat unresponsive 2	Neutral 3	Somewhat responsive 4	Totally responsive 5	Unsure	Undecided
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Comments:

b. Are you concerned that you 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 have any other concerns regarding impact on others?
Write your 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 **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 you wish respected.

b. How important is **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** you wish respected.

c. How important is your **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 **any beliefs** you wish respected.

d. What concerns, scares or worries you the most is:

e. Describe any other values or beliefs you have regarding your medical care:

Flexibility in Decision Making:

How much flexibility in decision making do you want your SDM to have:



Total Flexibility

this is a guide, my
SDM has total
flexibility in
deciding what I
would want

No Flexibility

I want these
wishes
followed as
closely as
possible

Date: _____

Signature: _____

Witness #1 _____

Witness #2 _____