

Appendix A



Graphic Values History

Questions for Patients - *Print Version*

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Values History Process

The values history process is made up of 4 steps.

Step 1. Patient

1. Patient chooses the format most comfortable completing the GVH – paper, laptop, tablet
2. Researcher
 - a. Orients patient to the GVH.
 - b. Instructs patient to complete the GVH based on his/her values.
3. Patient completes the Graphic Values History for patients, without SDM input.
 - a. If necessary researcher provides assistance completing document
 - i. Acting as a scribe
 - ii. Answering questions

Step 2. Substitute Decision Maker

1. SDM chooses the format most comfortable completing the GVH – paper, laptop, tablet
2. Researcher
 - a. Orients SDM to the GVH.
 - b. Instructs SDM to complete the GVH based on his/her understanding of the patient's values.
3. SDM completes the Graphic Values History for SDMs, without patient input.
 - a. If necessary researcher provides assistance completing document
 - i. Acting as a scribe
 - ii. Answering SDM's questions

Step 3. Facilitated Discussion

1. Researcher will facilitate discussion of GVH responses, comparing
 - a. Patient responses
 - b. SDM responses
2. Intent of the facilitated discussion is for:
 - a. SDM to hear the patient's responses, and why
 - b. Patient to hear SDM's responses, and why
 - c. SDM to understand patient values
3. If appropriate/necessary GVH can be updated
4. Advise the Patient and SDM to keep the GVH and update as necessary
5. Advise the SDM to bring the GVH to the hospital if the patient is admitted

Step 4. Decision Making

The substitute decision maker's responsibility for decision making begins when the patient is no longer capable to make decisions and needs treatment decisions made. The doctor caring for the patient will make this determination. At this time the substitute decision maker should use the GVH to determine what the patient would want in the situation. Making decisions based on applicable wishes is what is required under the Health Care Consent Act and demonstrates respect for the patient.

Demographics

1. What is your age?

< 20 yrs

21 - 30 yrs

31 - 40 yrs

41 - 50 yrs

51 - 60 yrs

71 - 70 yrs

71+ yrs

2. Please provide a brief description of your **current health condition**:

3. How long have you been living with your current condition?

< 1 yr

1 - 5 yrs

6 - 10 yrs

11 - 19 yrs

20 +

Graphic Values History

4. What is your gender?

Female

Male

5. What is the highest level of education you completed?

Nursery school to Gr. 8

Some high school, no diploma

High school graduate, diploma or equivalent

Some college credit, no degree

Trade/technical/vocational training

Bachelor's degree

Master's degree

Professional degree

Doctorate degree

6. Over the last 6 months, did you find it difficult to pay for all of the following: prescription medications, home heating, adequate food or home care, rent/mortgage payments?

Yes

No

Graphic Values History

Definition

A values history is a document that asks questions to help you think about **your** values and preferences. It helps you identify what is important to you. The completed document can help guide your substitute decision maker (SDM, e.g., POA, spouse) in the event you are not able to make decisions.

Introduction

This graphic values history is intended to assist you in thinking about your personal values.

There are eight sections to the graphic values history:

1. Quality of Life - Independence
2. Quality of Life - Medical Condition
3. Value Conflicts - Part 1
4. Value Conflicts - Part 2
5. Are some conditions worse than death?
6. How do you weigh chances of survival?
7. Impact of decisions on others
8. Religious / Spiritual / Cultural Beliefs

Please take as much time as you need to complete this graphic values history. While adding comments takes time, this provides valuable information to your substitute decision maker about what you were thinking. You are not required to answer every question; however, doing so will give useful information to your treatment team and to your substitute decision maker in the event that you are not able to make decisions for yourself. This document can be used along with a “Living Will” or other statement of treatment wishes.

In the event that you are found to be incapable of making treatment decisions, your substitute decision maker will be required to follow your previously expressed wishes which are applicable to the circumstances. This is why it is important to discuss your values by reviewing this document with your SDM.

If you change your mind, revise your values history and discuss the changes with your substitute decision maker


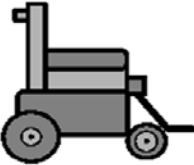




1. Quality of Life - Dependence - Independence†

Definition


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

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 circumstance, with **no reasonable chance of improvement**.

Instructions: Circle the most appropriate answer.

What would I say about my quality of life if I were . . .			Totally Unacceptable	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
a. Unable to walk, could only get around by wheelchair			1	2	3	4	5
<i>Comments</i>							
b. Unable to feed myself			1	2	3	4	5
<i>Comments</i>							
c. Unable to wash myself			1	2	3	4	5
<i>Comments</i>							

Graphic Values History

What would I say about my quality of life if I were . . .			Totally Unacceptable	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
d. Unable to make my own decisions			1	2	3	4	5
Comments:							
e. Not able to return to the place where I lived before I got sick			1	2	3	4	5
Comments:							

† 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



2. Quality of Life - State of Health

Definition


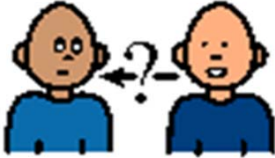
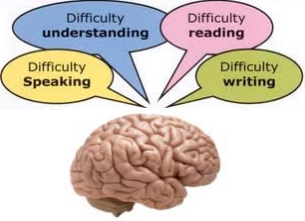
Quality of life - The degree of satisfaction, comfort and enjoyment in life, what makes life worth living.

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**.



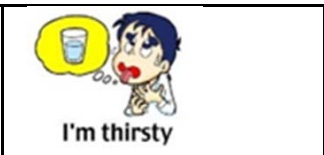

Instructions: Circle the most appropriate answer.

What would I say about my quality of life if I were . . .		Totally Unacceptable	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
a. Unable to swallow safely		1	2	3	4	5
Comments						
b. Fed by tube into the stomach		1	2	3	4	5
Comments						

Graphic Values History

What would I say about my quality of life if I were . . .		Totally Unacceptable	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
c. Unable to understand what others say (Able to hear the voice or see print, but I can't make sense of the words)		1	2	3	4	5
Comments						
d. Unable to communicate my thoughts (know what I want to say, but have trouble saying or writing)		1	2	3	4	5
Comments:						
e. Unable to speak or understand speech and unable to read or write.		1	2	3	4	5
Comments:						

Graphic Values History

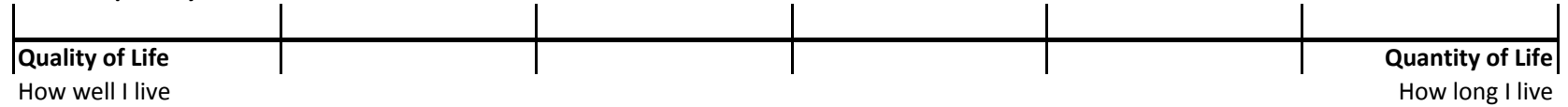
What would I say about my quality of life if I were . . .		Totally Unacceptable	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
f. In constant physical pain		1	2	3	4	5
Comments:						
g. Constantly short of breath		1	2	3	4	5
Comments:						
h. Constantly thirsty		1	2	3	4	5
Comments:						
i. Constantly nauseated (feel like I'm going to throw up)		1	2	3	4	5
Comments:						

3. Questions exploring value conflicts (part 1) †

When two values conflict, which value takes priority (more important)?

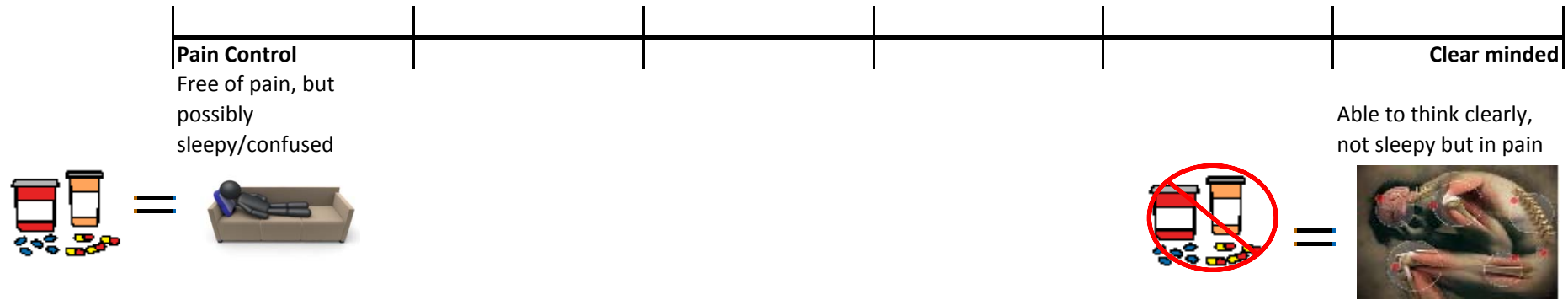
Instructions: Circle the point on the **line** (range) that shows which value is most important to you.

a. What would I say is more important -- **quality of life** or **quantity of life**?



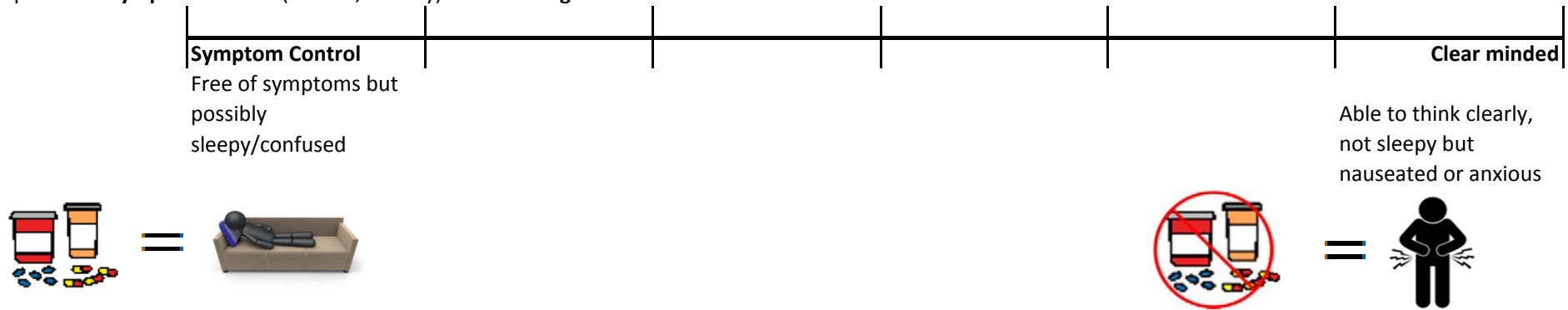
Comments:

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?**



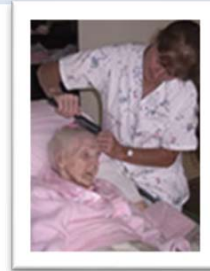
Comments:

4. Questions exploring value conflicts (part 2)

When two values conflict, which value takes priority (most important)? How do you assess quality of life under the following circumstances?

Instructions: Circle the most appropriate answer.

a. What would I say if my illness meant that 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	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
1	2	3	4	5

Comments:

b. What would I say if I were no longer able to make decisions for myself or look after myself, but I could recognize family?



Totally Unacceptable	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
1	2	3	4	5

Comments:

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c. What would I say if I were no longer able to make decisions for myself or look after myself, **and** was **not awake** or able to recognize my family?



Totally Unacceptable	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
1	2	3	4	5

Comments:

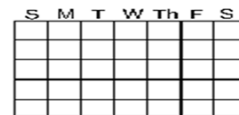
d. Would I say it was worth going through **invasive** treatment to live **one more day**?



Totally Unacceptable	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
1	2	3	4	5

Comments:

e. Would I say it was worth going through **invasive** treatment to live **one more month**?



Totally Unacceptable	Somewhat Unacceptable	Uncertain	Somewhat Acceptable	Totally Acceptable
1	2	3	4	5




Comments:

Invasive - a treatment that involves putting something into the body or cutting 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 worksheet looks at such situations. In each situation described below, ask yourself: what would I want if the treatment would **NOT reverse or improve my condition**?




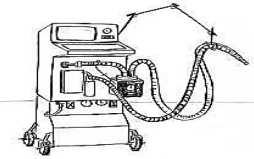
Instructions: Circle the most appropriate answer.

What if I ...		Definitely do not want treatment that prolongs life	May not want treatment that prolongs life	Uncertain	May want treatment that prolongs life	Definitely want treatment that prolongs life
a. Could no longer recognize (know) or interact (talk or do things with) with family or friends.		1	2	3	4	5
Comments						
b. Could no longer think or speak clearly.		1	2	3	4	5
Comments						
c. Could no longer respond to commands or requests.		1	2	3	4	5
Comments						




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What if I ...		Definitely do not want treatment that prolongs life	May not want treatment that prolongs life	Uncertain	May want treatment that prolongs life	Definitely want treatment that prolongs life
d. Could no longer walk, but could get around in a wheelchair.		1	2	3	4	5
Comments						
e. Could no longer get outside and must spend all day at home.		1	2	3	4	5
Comments						
f. Was in severe untreatable physical pain most of the time.		1	2	3	4	5
Comments						



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What if I ...		Definitely do not want treatment that prolongs life	May not want treatment that prolongs life	Uncertain	May want treatment that prolongs life	Definitely want treatment that prolongs life
g. Was in severe discomfort (such as nausea, diarrhea) most of the time .		1	2	3	4	5
Comments						
h. Needed a feeding tube to stay alive.		1	2	3	4	5
Comments						
i. Need to be connected to a machine 4 - 6 hours per treatment, 3 treatments per week. Treatments clean my blood and remove fluid		1	2	3	4	5
Comments						
j. Need to be connected to a breathing machine 24 hrs a day in order to breathe		1	2	3	4	5

Graphic Values History

What if I ...		Definitely do not want treatment that prolongs life	May not want treatment that prolongs life	Uncertain	May want treatment that prolongs life	Definitely want treatment that prolongs life
Comments						
k. Needed someone to take care of me 24 hours a day.		1	2	3	4	5
Comments						
l. Could no longer control my bladder.		1	2	3	4	5
Comments						
m. Could no longer control my bowels.		1	2	3	4	5
Comments						
n. Lived permanently in a nursing home.		1	2	3	4	5

Graphic Values History

What if I ...		Definitely do not want treatment that prolongs life	May not want treatment that prolongs life	Uncertain	May want treatment that prolongs life	Definitely want treatment that prolongs life
Comments						
o. Was confined to bed.		1	2	3	4	5
Comments						
p. Lived permanently in a Critical Care Unit.		1	2	3	4	5
Comments						
q. Other.		1	2	3	4	5
Comments						

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

6. How do I weigh my chances of survival? ‡

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 than before you became ill?

Imagine: You are seriously ill. Doctors are recommending treatment that has harsh side effects, such as severe pain, nausea, vomiting, or weakness that could last for months. Treatment would allow you to recover from this illness, **but your overall condition would probably be somewhat worse than before you became ill (i.e., recovery but a decline in condition)**. Refusal of treatment would result in death.

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

Instructions: Circle the most appropriate answer for each situation

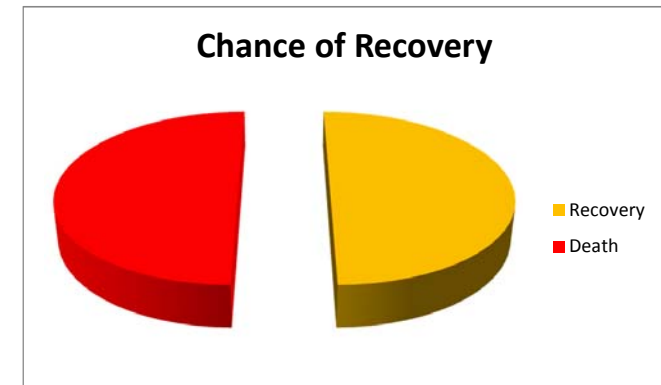
	Definitely not	Probably not	Uncertain	Probably would	Definitely would
a. High: over 80% chance I would recover to somewhat poorer health than before I got sick	1	2	3	4	5

Comments:



	Definitely not	Probably not	Uncertain	Probably would	Definitely would
b. Moderate: 50% chance I would recover to somewhat poorer health than before I got sick	1	2	3	4	5

Comments



	Definitely not	Probably not	Uncertain	Probably would	Definitely would
c. Low: 20% chance I would recover to somewhat poorer health than before I got sick	1	2	3	4	5

Comments:



	Definitely not	Probably not	Uncertain	Probably would	Definitely would
d. Very, Very Low : less than 1 in 1000 or .1% chance I would recover to somewhat poorer health than before I got sick	1	2	3	4	5

Comments:



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




7. Impact of Decision on Others

Most of us live within relationships (e.g., family, friends). As such our decisions impact others (i.e, financially, physically, emotionally).

Instructions: Circle the most appropriate answer.

<p>a. Do you think your family and friends will support you with the implementation of your wishes?</p>		<p>Totally Unsupportive</p>	<p>Somewhat Unsupportive</p>	<p>Uncertain</p>	<p>Somewhat Supportive</p>	<p>Totally Supportive</p>
		<p>1</p>	<p>2</p>	<p>3</p>	<p>4</p>	<p>5</p>
<p>Comments:</p>						
<p>b. How much do you think your decisions will impact your family and friends?</p>		<p>To a Great Extent</p>	<p>Somewhat</p>	<p>Uncertain</p>	<p>Very Little</p>	<p>Not At All</p>
		<p>1</p>	<p>2</p>	<p>3</p>	<p>4</p>	<p>5</p>
<p>Comments:</p>						



Graphic Values History

c. How concerned are you about being a:		Greatly Concerned	Concerned	Uncertain	Not Concerned	Not at all Concerned
i. Financial burden?		1	2	3	4	5
Comments:						
ii. Physical burden?		1	2	3	4	5
Comments:						
iii. Emotional burden?		1	2	3	4	5
Comments:						

8. Religious / Spiritual / Cultural Beliefs

Religious / Spiritual beliefs play an important role in end of life decision making for some people. For others, Religious / Spiritual beliefs are not important at this time.

Instructions: Please circle the best answer .

<p>a. What importance do religious / spiritual beliefs play in guiding your medical treatment?</p>		<p>Not Important</p>	<p>Of Little Importance</p>	<p>Uncertain</p>	<p>Important</p>	<p>Very Important</p>
		<p>1</p>	<p>2</p>	<p>3</p>	<p>4</p>	<p>5</p>
<p>Please describe religious/spiritual beliefs you wish respected.</p>						
<p>b. What importance do cultural practices play in guiding your medical treatment?</p>		<p>Not Important</p>	<p>Of Little Importance</p>	<p>Uncertain</p>	<p>Important</p>	<p>Very Important</p>
		<p>1</p>	<p>2</p>	<p>3</p>	<p>4</p>	<p>5</p>
<p>Please describe cultural practices you wish respected.</p>						

c. The thing that concerns, scares or worries you the most is:

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

Statement:

This document represents my values. I want my substitute decision-maker to use my values when making decisions about my health care.

Date: _____

Signature: _____

Witness #1 _____

Witness #2 _____