

Advance Care Planning Engagement survey

Substitute Decision-Maker Version

Version October 19, 2017

(15 items with 3 constructs- Decisional role, Contemplation, Readiness + 2 items [thought about talking to doctor about medical care, readiness to talk to about situations] to maintain symmetry = 17 items)

You are being asked to complete this survey because you are a friend, family member, or loved one of a person who may need medical decisions made in the future if they cannot speak for themselves. This survey will refer to that person as your loved one.

A substitute decision maker is a family member or friend who can make decisions for another person if that person is not mentally capable of making their own decisions regarding health care.

Over the next few sections we will be asking you about 3 topics:

- 1. Knowing about substitute decision makers**
- 2. How much you have thought being a substitute decision maker for your loved one**
- 3. Readiness to be a substitute decision maker for your loved one**

Section 1. Knowing about Substitute Decision Makers

1. How well informed are you about who can be a substitute decision maker?

Not at all	A little	Somewhat	Fairly	Extremely
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2. How well informed are you about what makes someone a good substitute decision maker?

Not at all	A little	Somewhat	Fairly	Extremely
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3. How well informed are you about the types of decisions that you may have to make for your loved one in the future?

Not at all	A little	Somewhat	Fairly	Extremely
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Section 2. The next questions ask how much you have thought about being a substitute decision maker for your loved one

4. How much have you thought about your role as your loved one's substitute decision-maker?

Never	Once or twice	A few times	Several times	A lot
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5. How much have you thought about talking with your loved one about whether or not there are certain health situations that would make your loved one's life not worth living?

Never	Once or twice	A few times	Several times	A lot
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6. How much have you thought about being part of a discussion with your loved one's DOCTORS about whether or not there are certain health situations that would make your loved one's life not worth living?

Never	Once or twice	A few times	Several times	A lot
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7. How much have you thought about talking with your loved one about the care he/she would want if they were very sick or near the end of life?

Never	Once or twice	A few times	Several times	A lot
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8. How much have you thought about being part of a discussion with your loved one's DOCTORS about the care your loved one would want if he/she was very sick or near the end of life?

Never	Once or twice	A few times	Several times	A lot
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9. As of today, how confident are you that today you could serve as loved one's substitute decision maker?

Not at all	A little	Somewhat	Fairly	Extremely
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10. As of today, how confident are you that you could talk with your loved one about the care he/she would want if he/she were very sick or near the end of life?

Not at all	A little	Somewhat	Fairly	Extremely
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11. As of today, how confident are you that you could be part of a discussion with your loved one's DOCTORS about the care your loved one would want if he/she were very sick or near the end of life?

Not at all	A little	Somewhat	Fairly	Extremely
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Section 3. The next questions ask about how ready you are to be a substitute decision maker for your loved one

12. How ready are you to formally discuss with your loved one your role as their substitute decision maker?

- a. I have never thought about it
- b. I have thought about it, but I am not ready to do it
- c. I am thinking about doing it in the next 6 months
- d. I am definitely planning to do it in the next 30 days
- e. I have already done it

13. How ready are you to talk to your loved one about whether or not there are certain health situations that would make your loved one's life not worth living?

- a. I have never thought about it
- b. I have thought about it, but I am not ready to do it
- c. I am thinking about doing it in the next 6 months
- d. I am definitely planning to do it in the next 30 days
- e. I have already done it

- 14. How ready are you to talk to your loved one about the kind of medical care he/she would want if they were very sick or near the end of life?**
- a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it
- 15. How ready are you to be part of a discussion with your loved one's DOCTOR about whether or not there are certain health situations that would make your loved one's life not worth living?**
- a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it over the next few visits
 - d. I am definitely planning to do it at the next visit
 - e. I have already done it
- 16. How ready are you to be part of a discussion with your loved one's DOCTOR about the kind of medical care your loved one would want if he/she were very sick or near the end of life?**
- a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it
- 17. How ready are you to ask your loved one's DOCTOR questions to help you make a good medical decision for your loved one if your loved one was unable to speak for themselves?**
- a. I have never thought about it
 - b. I have thought about it, but I am not ready to do it
 - c. I am thinking about doing it in the next 6 months
 - d. I am definitely planning to do it in the next 30 days
 - e. I have already done it