

## Care Planning for Individuals with Dementia

Our research center is conducting a survey on care planning for individuals who have problems with their memory or have been diagnosed with dementia. We are asking you to take part in this survey because you are a study partner (or informant) for a person with memory problems or dementia. We are interested in your opinions and views on making health care decisions for this person. Please answer the survey questions as best you can.

Thank you for taking part in this survey.

---

**First are a set of statements about dementia and Alzheimer's disease. For each statement, indicate whether you think the statement is True or False. If you are not sure of the right answer, make your best guess. It is important to provide an answer for every statement.**

- |     |      |       |   |
|-----|------|-------|---|
| 1.  | True | False | Alzheimer's disease is one type of dementia.  |
| 2.  | True | False | If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease.                             |
| 3.  | True | False | Trouble handling money or paying bills is a common early symptom of Alzheimer's disease.  |
| 4.  | True | False | When a person with dementia becomes agitated, a medical examination might reveal other health problems that caused the agitation.   |
| 5.  | True | False | In rare cases, people have recovered from Alzheimer's disease.  |
| 6.  | True | False | Once people have dementia due to Alzheimer's disease, they are no longer capable of making informed decisions about their own care. |
| 7.  | True | False | When people with dementia begin to have difficulty taking care of themselves, caregivers should take over right away.               |
| 8.  | True | False | Alzheimer's disease cannot be cured.  |
| 9.  | True | False | Eventually, a person with dementia due to Alzheimer's disease will need 24-hour supervision.  |
| 10. | True | False | After symptoms of dementia due to Alzheimer's disease appear, the average life expectancy is 6 to 12 years.                         |

**The next two items ask about the extent to which you agree or disagree with statements about dementia.**

11. “Individuals with dementia will have more difficulty making medical decisions for themselves as their disease progresses.” Would you say...

Strongly Agree     Agree     Undecided     Disagree     Strongly Disagree

12. “Knowing what to expect as dementia progresses can help patients and families plan for medical decisions in the future.” Would you say...

Strongly Agree     Agree     Undecided     Disagree     Strongly Disagree

13. **The next three items ask about your current level of knowledge about what happens to individuals in the different stages of dementia?**

How would you describe your knowledge of what happens to individuals in each of the following stages of dementia?	Would you say...			
	I know a lot	I know some things	I know very little	I know nothing
a. <u>Mild stage</u> when memory problems, like forgetting conversations, are noticeable to family or friends.				
b. <u>Moderate stage</u> when help is needed with some day-to-day activities, like preparing sandwiches.				
c. <u>Severe or late stage</u> when extensive help is needed with daily activities, like bathing or eating.				

**Now we would like to ask for your opinions regarding learning about dementia**

14. Dementia progresses through different stages, from mild to moderate and then to the severe or late stage of disease. In your opinion, when is the best time for health care providers to inform patients with dementia about what happens in the late stage of the disease? Would you say...

- 1. When the patient first gets the diagnosis
- 2. About a year after the patient has had the diagnosis
- 3. After the patient has had the disease for a few years
- 4. When the patient enters the end-stage of the disease
- 5. Never
- 9. Don't know

15. When is the best time for health care providers to inform family members of a patient with dementia about what happens in the late stage of the disease? Would you say...

- 1. When the patient first gets the diagnosis
- 2. About a year after the patient has had the diagnosis
- 3. After the patient has had the disease for a few years
- 4. When the patient enters the end-stage of the disease
- 5. Never
- 9. Don't know

16. As a study partner or informant for someone with memory problems or dementia, to what extent would you like to know more about what happens to patients in the late stage of the disease? Would you say...

- 1. I would like to know more
- 2. I am not sure if I want to know more
- 3. I don't want to know more
- 9. Don't know

**The next questions ask about the individual (the person who has memory problems or dementia) for whom you are a study partner or informant.**

17. How would you describe his/her stage of memory problems at the present time?

- 1. No memory problems
- 2. Some memory problems, but no dementia diagnosis
- 3. Mild stage of dementia
- 4. Moderate stage of dementia
- 5. Severe or late stage of dementia
- 9. Don't know

18. To what extent do you feel he/she is capable of participating in medical decisions about his/her health at the present time?

- 1. Fully capable
- 2. Mostly capable
- 3. Somewhat capable
- 4. Not at all capable
- 9. Don't know

19. To what extent do you feel he/she will be capable of participating in medical decisions about his/her health one year from now?
- 1. Fully capable
  - 2. Mostly capable
  - 3. Somewhat capable
  - 4. Not at all capable
  - 9. Don't know
20. To what extent do you feel he/she will be capable of participating in medical decisions about his/her health five years from now?
- 1. Fully capable
  - 2. Mostly capable
  - 3. Somewhat capable
  - 4. Not at all capable
  - 9. Don't know
21. Sometimes people chose a person to be their health care proxy if they are unable to make their own medical decisions in the future. Are you the person chosen to be his/her health care proxy (the person to make medical decisions if he/she is unable to)?
- 1. Yes
  - 2. No
  - 9. Don't know
22. Has he/she completed a legal document (known as a medical power of attorney) that names a health care proxy (a person to make medical decisions if he/she is unable to)?
- 1. Yes
  - 2. No
  - 9. Don't know
23. Sometimes people fill out paperwork describing the sort of medical treatments they do or do not want if they cannot participate in decision-making in the future. This type of document is often called a living will.
- As far as you know, has he/she completed a written living will or similar document?
- 1. Yes
  - 2. No
  - 9. Don't know

24. Have you had a discussion with him/her about the type of medical treatments he/she would want or not want if he/she could no longer make treatment decisions?

- 1. Yes
- 2. No
- 9. Don't know

**The following statements are about three types of medical care that may be mentioned in a living will. The two next questions that follow these statements refer to these three types of medical care.**

Sometimes, physicians ask patients or family members to choose between three general levels of medical care: **Intensive medical care**, **Basic medical care**, and **Comfort care**. Each level is described below:

**Intensive medical care** includes the use of all available medical treatments, including cardiopulmonary resuscitation (CPR), breathing machines, feeding tubes, hospitalization and admission to an intensive care unit (ICU) if necessary.

**Basic medical care** includes some, but not all, available medical treatments. Patients may be treated with antibiotics, fluids, and may be sent to the hospital for sudden illnesses. People choosing basic care would NOT want CPR, breathing machines, tube-feeding or treatment in an ICU.

**Comfort care** treatments are used to relieve uncomfortable symptoms. Patients may be given medications to relieve pain, or oxygen to assist their breathing. People choosing comfort care do NOT want CPR, breathing machines, tube-feeding, or fluids or medications given through a tube placed in a vein. With comfort care, hospitalization is avoided unless it is needed to relieve pain.

**The following questions are again about the person who has memory problems or dementia and for whom you are a study partner or informant.**

25. Which of the following best describes the level of medical care you believe he/she wants at the present time?

- 1. Intensive medical care that uses all available medical treatments
- 2. Basic medical care that includes some but not all available medical treatments
- 3. Comfort care that is used to just relieve symptoms of discomfort
- 9. Don't know

26. Which of the following best describes the level of medical care you believe he/she would want at the end stage of illness near the end of life?

- 1. Intensive medical care that uses all available medical treatments
- 2. Basic medical care that includes some but not all available medical treatments
- 3. Comfort care that is used to just relieve symptoms of discomfort
- 9. Don't know

27. Do you think there should be further discussion between you and him/her about the type of medical treatments he/she would want or not want?

- 1. Yes
- 2. No
- 3. No, because he/she is no longer capable of having that discussion
- 9. Don't know

28. Has a health care provider, such as a doctor or nurse, had a discussion with him/her about the type of medical treatments he/she would want or not want?

- 1. Yes
- 2. No
- 9. Don't know

29. Do you think there should be further discussion between him/her and his/her doctor about the type of medical treatments he/she would want or not want?

- 1. Yes
- 2. No
- 3. No, because he/she is no longer capable of having that discussion
- 9. Don't know

30. The following statements are about discussing end-of-life care and treatment options with family members of the person who has memory problems or dementia.

For each statement, indicate <u>how much you agree</u> with that statement.	Would you say...				
	I strongly agree	I somewhat agree	I neither agree nor disagree	I somewhat disagree	I strongly disagree
a. My family members would support the level of treatment that he/she would or would not want at the end of life.					
b. My family is able to openly discuss issues about end-of-life care.					
c. In my family, we feel each member should make his/her own end-of-life care decisions.					
d. Members of my family would be better able to discuss end-of-life care and treatment options if they had more information					
e. My family strives to agree on important decisions					

31. What is the religious or spiritual affiliation of the person for whom you are a study partner or informant who has memory problems or dementia?

- 1. Christian (if Christian, what is his/her Christian denomination?)
  - 1a. Roman Catholic
  - 1b. Eastern Orthodox (or Orthodox Catholic)
  - 1c. Protestant (e.g., Baptist, Methodist, Pentecostal, Nondenominational)
  - 1d. Other Christian denomination (specify): \_\_\_\_\_
- 2. Jewish
- 3. Muslim
- 4. Buddhist
- 5. Hindu
- 6. Other (specify): \_\_\_\_\_
- 7. No religious or spiritual affiliation
- 9. Don't know

32. To what extent do you feel his/her religious or spiritual beliefs influence what medical treatments he/she would want or not want?

- 1. A great deal
- 2. Somewhat
- 3. A little bit
- 4. Not at all
- 9. Don't know

**The next questions are about you.**

33. What is your religious or spiritual affiliation?

- 1. Christian (if Christian, what is your Christian denomination?)
  - 1a. Roman Catholic
  - 1b. Eastern Orthodox (or Orthodox Catholic)
  - 1c. Protestant (e.g., Baptist, Methodist, Pentecostal, Nondenominational)
  - 1d. Other Christian denomination (specify): \_\_\_\_\_
- 2. Jewish
- 3. Muslim
- 4. Buddhist
- 5. Hindu
- 6. Other (specify): \_\_\_\_\_
- 7. No religious or spiritual affiliation

**The next two questions refer to the person who has memory problems or dementia and for whom you are a study partner or informant.**

34. If you were to make medical decisions for him/her, to what extent do you feel your religious or spiritual beliefs would influence those decisions?

- 1. A great deal
- 2. Somewhat
- 3. A little bit
- 4. Not at all
- 9. Don't know

35. If his/her health care provider said that he/she is in the end stage of the disease, would you trust and accept that opinion?

- 1. Completely
- 2. Somewhat
- 3. A little bit
- 4. Not at all
- 9. Don't know

36. Which of the following statements best describes your level of knowledge about hospice care, which is an approach to care that is focused primarily on quality of life and comfort near the end of life.

- 1. I know a lot about hospice
- 2. I know some things about hospice
- 3. I know very little about hospice
- 4. I don't know anything about hospice

37. Based on your understanding, which of the following statements describes hospice care?

*(You may select one or more than one answer.)*

- 1. Hospice care focuses on caring, not curing
- 2. Hospice care can be provided at home, in a hospice center or in a nursing home
- 3. Hospice care includes managing the patient's pain and symptoms
- 4. Hospice care provides bereavement care and counseling to family and friends
- 9. Don't know

38. The following statements are about the use of hospice care near the end of life.

For each statement, indicate <u>how much you agree</u> with that statement.	Would you say...				
	<b>I strongly agree</b>	<b>I somewhat agree</b>	<b>I neither agree nor disagree</b>	<b>I somewhat disagree</b>	<b>I strongly disagree</b>
a. Hospice care relieves suffering.					
b. Hospice care speeds up or quickens the dying process.					
c. A decision to use hospice care is giving up.					

39. When do you believe that hospice care is a worthwhile option?

*(You may select one or more than one answer.)*

- 1. When suggested by a physician
- 2. When suggested by the patient
- 3. When suggested by a close relative or friend
- 4. Never
- 9. Don't know

40. We would like to know your general level of comfort with the topics of this survey. Overall, how comfortable did you feel answering the questions in this survey? Would you say...

- 1. Very comfortable
- 2. Somewhat comfortable
- 3. A little uncomfortable
- 4. Very uncomfortable

41. Would having more information about the stages of dementia, health care decision-making, treatment options or end-of-life care help you with making decisions for the person who has memory problems or dementia for whom you are a study partner or informant?

- 1. Yes, more information would be helpful
- 2. No, I do not need more information (*If no, skip to end of survey*)

41a. If yes, what topics would be most helpful to you at the present time?

*(You may select one or more than one item.)*

- Stages of dementia and what usually happens as dementia progresses
- Health care decision-making and treatment options
- End-of-life care for persons with dementia
- Financial issues related to caring for someone with dementia
- Legal issues related to caring for someone with dementia

41b. If yes, please check which of the following ways of providing information about dementia, health care decision-making, treatment options, end-of-life care, financial or legal issues would be helpful to you or family members.

*(You may select one or more than one item.)*

- |   |   |
|---|---|
| <input type="checkbox"/> Brochures              | <input type="checkbox"/> Social media                           |
| <input type="checkbox"/> Videos                 | <input type="checkbox"/> Conversation with clergy               |
| <input type="checkbox"/> Educational seminars   | <input type="checkbox"/> Conversation with health care provider |
| <input type="checkbox"/> Other (specify): _____ |   |
- 

Thank you for your time and responses to this survey. We greatly appreciate your help.

*AD Center staff to complete the following items based on NACC Uniform Data Set*

### Demographic Information

#### AD Center Subject:

1. **Sex:**

- \_\_\_\_ 1 Male  
\_\_\_\_ 2 Female

2. **Age:**

Month/Year of birth: \_\_\_\_ / \_\_\_\_

3. **Years of Education:**

Report achieved level using the codes below; if an attempted level is not completed, enter the number of years attended. High school/GED = 12; Bachelor's degree = 16; Master's degree = 18; Doctorate = 20 years:

\_\_\_\_ (99 = *unknown*)

4. **Ethnicity:**

Does the subject report being Hispanic/Latino (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?

- \_\_\_\_ 1 Yes  
\_\_\_\_ 0 No  
\_\_\_\_ 9 Unknown

5. **Race:**

- \_\_\_\_ 1 White  
\_\_\_\_ 2 Black or African American

6. **CDR Rating:**

- \_\_\_\_ 1  
\_\_\_\_ 2  
\_\_\_\_ 3

7. **Dementia type (Primary Dx):**

- \_\_\_\_ 1 AD  
\_\_\_\_ 2 FTLT  
\_\_\_\_ 3 DLB  
\_\_\_\_ 4 Other (specify): \_\_\_\_\_

Study Partner:

1. **Sex:**

- 1 Male  
 2 Female

2. **Age:**

Month/Year of birth: \_\_\_ / \_\_\_

3. **Years of Education:**

Report achieved level using the codes below; if an attempted level is not completed, enter the number of years attended. High school/GED = 12; Bachelor's degree = 16; Master's degree = 18; Doctorate = 20 years:

\_\_\_ (99 = *unknown*)

4. **Ethnicity:**

Does the study partner report being Hispanic/Latino (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?

- 1 Yes  
 0 No  
 9 Unknown

5. **Race:**

- 1 White  
 2 Black or African American

6. **Study partner's relationship to subject:**

- |   |   |
|---|---|
| <input type="checkbox"/> 1 Spouse/partner | <input type="checkbox"/> 4 Other relative         |
| <input type="checkbox"/> 2 Child          | <input type="checkbox"/> 5 Friend/neighbor        |
| <input type="checkbox"/> 3 Sibling        | <input type="checkbox"/> 7 Other (specify): _____ |

7. **Does study partner live with the subject?**

- 1 Yes  
 0 No

7a. If no, approximate frequency of in-person visits:

- |   |   |
|---|---|
| <input type="checkbox"/> 1 Daily            | <input type="checkbox"/> 4 At least 3x/month      |
| <input type="checkbox"/> 2 At least 3x/week | <input type="checkbox"/> 5 Monthly                |
| <input type="checkbox"/> 3 Weekly           | <input type="checkbox"/> 6 Less than once a month |

7b. If no, approximate frequency of telephone contact:

- |   |   |
|---|---|
| <input type="checkbox"/> 1 Daily            | <input type="checkbox"/> 4 At least 3x/month      |
| <input type="checkbox"/> 2 At least 3x/week | <input type="checkbox"/> 5 Monthly                |
| <input type="checkbox"/> 3 Weekly           | <input type="checkbox"/> 6 Less than once a month |