



Early Stage Alzheimer's – Your Work and Benefits Experiences

As Early Stage Alzheimer's patients, we are working in cooperation with the national Alzheimer's Association to determine how dementia affects your ability to work and receive health insurance. We would appreciate your cooperation in completing this survey, which should take about 10-20 minutes. We will maintain your confidentiality. On behalf of the 5.1 million Americans with Alzheimer's disease, thank you very much for your participation.

1. Do you have a diagnosis of dementia?

Yes

No → you have completed the survey – thank you!

2. Were you employed when you first noticed symptoms of dementia?

Yes

No → you have completed the survey – thank you!

3. What is your diagnosis? _____

4. What was your age at the time of your diagnosis? _____

5. What is your current age? _____

6. What was the length of time from when you first noticed symptoms until you received your diagnosis?

_____ Years _____ Months

7. How many doctors were involved in obtaining your diagnosis? _____

8. In the course of obtaining a diagnosis:

	Yes	No	I don't know
Did you have a PET scan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you have an MRI?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you have a CAT scan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you have a SPECT scan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you take a neuro-psych battery of tests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Was the result of the testing definitive? ie, stating that a dementia-related disorder was specifically identified from the test?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. What were your initial symptoms of dementia? Check all that apply:

- Memory problems
- Sleeplessness
- Depression
- Loss of smell
- Balance issues
- Speech issues
- Focus/concentration issues
- Other

10. Do you think these symptoms interfered with your work?

- Yes
- No

11. How long after you became aware of the symptoms do you think they began to interfere with your work?

_____ Years _____ Months

12. If you were self-employed at the time you began to notice symptoms, please go to #13

	Yes	No
Do you think your employer noticed the symptoms?	<input type="checkbox"/>	<input type="checkbox"/>
Did you talk with your employer or boss about the symptoms or their effect on your work?	<input type="checkbox"/>	<input type="checkbox"/>
Do you think your co-workers noticed the symptoms?	<input type="checkbox"/>	<input type="checkbox"/>
Did you talk with any co-workers about the symptoms or their effect on your work?	<input type="checkbox"/>	<input type="checkbox"/>
Did you talk with your care partner at home, if any, about the effect of the symptoms on your work?	<input type="checkbox"/>	<input type="checkbox"/>
Did you see a doctor about your symptoms while you were still working?	<input type="checkbox"/>	<input type="checkbox"/>

13. Were you still working when you obtained your diagnosis?

- No → go to #14
- Yes → go to #15

14. Which best describes why you were no longer working?

- I resigned from work because of my symptoms of dementia
- I took early retirement because of my symptoms of dementia
- I was terminated from my job because of my symptoms of dementia
- I left work or was terminated, but not because of my symptoms of dementia → go to #31 on page 6

15. Did you tell your employer or boss about your diagnosis?

- Yes
- No
- Not applicable - I was/am self-employed

16. Did you tell your co-workers about your diagnosis?

- Yes
- No

17. Did your employer have an employee assistance program (EAP)?

- Yes
- No
- I don't know

18. Did you use the EAP program?

- Yes
- No

19. Was the EAP program able to meet your needs?

- Yes
- No

20. Other comments regarding your EAP experience:

21. Were you aware of the Americans with Disabilities Act (ADA) laws and how they pertain to your situation?

- Yes
- No

22. Did your employer make accommodations?

- Yes
- No

23. If applicable, what were the accommodations that allowed you to continue working?

24. If applicable, what would have made it easier for you to continue working?

25. Did your employer require you to take a lesser-paying job within the company?

Yes

No

26. If yes, please describe

27. Did your employer offer disability income benefits?

Yes

No

28. Did your employer offer disability medical benefits?

Yes

No

29. Did you go on disability?

Yes

No

30. Was your disability:

Long-term

Short-term

Both

31. Do you currently have health insurance benefits? Check all that apply:

- Yes, through my employer or COBRA
- Yes, through my spouse/partner
- Yes, through the government (Medicare or Medicaid)
- No
- Other _____

32. If applicable, please describe how the loss of your health insurance affects you and your family.

33. Please explain the nature of the ongoing benefits (if any) from your employer.

34. Are you still working now?

- Yes → go to #41 on page 7
- No

35. Did your employer's insurance provider require you to apply for Social Security Disability benefits (SSDI)?

- Yes
- No

36. If applicable, how long did it take to obtain your Social Security Disability Benefits, or if you are still in the process, how long has it taken to date?

_____ Years _____ Months

37. If you applied for SSDI, please describe your SSDI application process

38. Did you consult an attorney?

Yes

No

39. Please describe your experience consulting an attorney:

40. If applicable, please describe how the loss of your job affects you and your family

41. If we have further questions about your experience, could we contact you?

Yes

No

First name _____

Last name _____

Email address _____

Phone number _____

The following demographic information is optional, but will help target resources and support:

57. What race/ethnicity do you use to describe yourself?

- White/Caucasian
- Black/African-American
- Latino/Hispanic
- Asian
- Other

58. Your gender

- Female
- Male

59. In what state do you live? _____

60. What is the highest level of education you have completed?

- Some high school or less
- High school graduate or GED
- Trade or vocational school
- Some college, no degree
- Associate's degree
- Bachelor's degree
- Advanced degree

61. What was your household income prior to your diagnosis?

- Less than \$10,000
- \$10,000 to \$14,999
- \$15,000 to \$24,999
- \$25,000 to \$34,999
- \$35,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 or more

62. What is your household income now (including any disability income)?

- Less than \$10,000
- \$10,000 to \$14,999
- \$15,000 to \$24,999
- \$25,000 to \$34,999
- \$35,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 or more

63. Have you used the services of your local Alzheimer's Association?

- Yes
- No

Thank you for taking this survey. We appreciate your feedback!