

The University of Iowa College of Nursing
Alzheimer's Family Involvement in Care Study

Caregiver Stress Inventory (CSI)

ID# _____
(4-9)

Date: _____
(10-13)

DIRECTIONS: Each of the statements in this questionnaire describes the behavior of an Alzheimer's resident or a circumstance of care. You are asked to indicate the extent to which each of the statements is currently a cause of stress for you as you care for Alzheimer's residents. Please circle the number on the scale provided that corresponds to the extent each statement describes a source of stress for you.

	<u>Not Stressful</u>						<u>Very Stressful</u>		<u>Col.</u>
1. Some residents are uncooperative due to not understanding my instructions.	1	2	3	4	5	6	7		(15)
2. Some residents do not urinate in the urinal or toilet.	1	2	3	4	5	6	7		(16)
3. Some residents constantly (or for frequent long periods) yell loudly or laugh shrilly.	1	2	3	4	5	6	7		(17)
4. Some residents strike or try to strike me.	1	2	3	4	5	6	7		(18)
5. Some residents rummage through or use staff belongings (e.g., staff lunch in refrigerator, uses staff restroom).	1	2	3	4	5	6	7		(19)
6. Some residents keep trying to go home or each day think they are going home.	1	2	3	4	5	6	7		(20)
7. Some residents become agitated when taken off the unit (e.g. in a car or to unfamiliar surroundings).	1	2	3	4	5	6	7		(21)
8. Some residents are constantly agitated and cannot be calmed.	1	2	3	4	5	6	7		(22)
9. Some residents require the attention of one staff person most of the time.	1	2	3	4	5	6	7		(23)
10. Some residents walk around dressed inappropriately.	1	2	3	4	5	6	7		(24)

	<u>Not Stressful</u>			<u>Very Stressful</u>				<u>Col.</u>
11. Some residents continue to repeat inappropriate behavior after staff have intervened and corrected them.	1	2	3	4	5	6	7	(25)
12. When a resident's mood changes suddenly.	1	2	3	4	5	6	7	(26)
13. When residents fall due to unsteadiness when standing or walking.	1	2	3	4	5	6	7	(27)
14. When residents are uncooperative even when they apparently understand instructions.	1	2	3	4	5	6	7	(28)
15. When residents constantly repeat "I'm hungry" or "I want food".	1	2	3	4	5	6	7	(29)
16. When residents' behaviors indicate that something is wrong, but they cannot tell you what.	1	2	3	4	5	6	7	(30)
17. When residents are so agitated and difficult to handle that I think I am doing my job badly.	1	2	3	4	5	6	7	(31)
18. When residents talk constantly.	1	2	3	4	5	6	7	(32)
19. When residents cuss me when I am delivering their care.	1	2	3	4	5	6	7	(33)
20. When residents require help to eat, but refuse help.	1	2	3	4	5	6	7	(34)
21. When residents require constant reminding to eat, bathe, or toilet.	1	2	3	4	5	6	7	(35)
22. I worry that residents will hurt themselves due to their constant agitation.	1	2	3	4	5	6	7	(36)
23. When residents have periods of extremely inappropriate behavior that lasts for several hours.	1	2	3	4	5	6	7	(37)
24. I worry that the care that is provided is not what the residents really need.	1	2	3	4	5	6	7	(38)

	<u>Not Stressful</u>			<u>Very Stressful</u>				<u>Col.</u>
25. When residents will not stay in bed at night.	1	2	3	4	5	6	7	(39)
26. When residents follow me or stay at my side all the time, asking questions, forgetting or not accepting my answers.	1	2	3	4	5	6	7	(40)
27. When a great deal of staff time and attention are required to complete simple tasks.	1	2	3	4	5	6	7	(41)
28. When residents rummage in other residents' rooms.	1	2	3	4	5	6	7	(42)
29. When residents are poorly groomed.	1	2	3	4	5	6	7	(43)
30. When residents require my attention even though I am busy with other necessary tasks.	1	2	3	4	5	6	7	(44)
31. When residents put their possessions in inappropriate places (e.g., toilet, waste basket).	1	2	3	4	5	6	7	(45)
32. When residents refuse their medication.	1	2	3	4	5	6	7	(46)
33. I am afraid residents will choke, aspirate or get pneumonia because they forget to swallow.	1	2	3	4	5	6	7	(47)
34. When residents will not stay in chairs or bed.	1	2	3	4	5	6	7	(48)
35. I feel I lack knowledge about how to best care for and help residents (e.g., how to help with eating, how to help maintain independence with ADL's).	1	2	3	4	5	6	7	(49)
36. The amount of patience needed to work with residents (e.g., the amount of time it takes, inappropriate behavior).	1	2	3	4	5	6	7	(50)
37. The lack of resources (agency commitment) to care appropriately for the residents.	1	2	3	4	5	6	7	(51)

	<u>Not Stressful</u>				<u>Very Stressful</u>			<u>Col.</u>
38. The lack of a unified approach among all disciplines and administration to care for and assume responsibility for the residents' care.	1	2	3	4	5	6	7	(52)
39. Visitors often do not understand the residents' behavior, do things to provoke agitation and I often do not know what I can do to counsel the visitors.	1	2	3	4	5	6	7	(53)
40. When residents are unpredictable (e.g., cooperative and calm and then suddenly angry, scream, grab or hit me).	1	2	3	4	5	6	7	(54)
41. I worry about residents irritating each other, getting into fights, and hurting each other.	1	2	3	4	5	6	7	(55)
42. The current physical arrangement for caring for the residents.	1	2	3	4	5	6	7	(56)
43. Being constantly reminded about how to respond to behavior of residents.	1	2	3	4	5	6	7	(57)

The University of Iowa College of Nursing
Family Involvement in Care Research

KNOWLEDGE OF ALZHEIMER'S TEST (KAT)
Key (Correct answer in **bold**)

I.D.# _____
(Col. 4-8)

Date: _____
(Col. 10-13)

Directions: Circle T if the statement is true or F if the statement is false.

CIRCLE ONE

- | | | | |
|--|----------|----------|------|
| 1. Memory loss is part of the normal aging process. | T | F | (15) |
| 2. Alzheimer's is a disease which progresses at an individual rate. | T | F | (16) |
| 3. Low stimulation is important to the individual with advanced Alzheimer's disease. | T | F | (17) |
| 4. The only loss produced by Alzheimer's disease is a progressive decline in memory. | T | F | (18) |
| 5. In the care setting, restraints are the best way to manage a demented patient who wanders. | T | F | (19) |
| 6. When a person with Alzheimer's disease shows signs of increasing confusion or stress, isolation is sometimes an appropriate management technique. | T | F | (20) |
| 7. Repeatedly asking questions is a symptom of the memory loss of Alzheimer's disease. | T | F | (21) |
| 8. The family with an Alzheimer's disease victim is often in a state of chronic grief. | T | F | (22) |
| 9. The T. V. is a good distracter for the patient with Alzheimer's disease. | T | F | (23) |
| 10. When a patient with Alzheimer's disease becomes accusatory, it is best to deny the accusation and remind the person of his disease process. | T | F | (24) |
| 11. Non-verbal cues are not important to the Alzheimer's disease patients because they depend more on communication content to assist function. | T | F | (25) |

CIRCLE ONE

- | | | | |
|---|----------|----------|------|
| 12. Environmental control is a prime intervention with persons with Alzheimer's disease. | T | F | (26) |
| 13. Individuals with Alzheimer's disease have a tendency to become more dependent on significant others. | T | F | (27) |
| 14. Maintaining a routine is important to the person with Alzheimer's disease. | T | F | (28) |
| 15. The family is an important source of information regarding pre-admission behaviors of the patient with Alzheimer's disease. | T | F | (29) |
| 16. Making the care setting more meaningful with family pictures is helpful to the victim of Alzheimer's disease. | T | F | (30) |
| 17. Physical exercise should be avoided by the person with Alzheimer's disease because it increases the person's stress level. | T | F | (31) |
| 18. Rest periods should not be planned for the patient with Alzheimer's disease in order to assure sleeping throughout the night. | T | F | (32) |
| 19. Generally, the cause for disruptive behaviors in the patient with Alzheimer's disease is the loss of ability to cope with stress. | T | F | (33) |
| 20. The patient with advanced Alzheimer's disease has insight into their behaviors. | T | F | (34) |
| 21. The cerebral cortex is the area of the brain where pathological changes are most often found with Alzheimer's disease. | T | F | (35) |
| 22. Alzheimer's disease is easily diagnosed with laboratory tests and X-ray. | T | F | (36) |
| 23. There is research evidence that large amounts of Lecithin or other Choline sources used early in the disease process are beneficial in treating Alzheimer's patients. | T | F | (37) |
| 24. Radios and TVs are usually good ways to keep Alzheimer's patients in touch with the world. | T | F | (38) |

CIRCLE ONE

25. Alzheimer's patients should stay in bed all night so that they can get their sleep. **T** **F** (39)
26. Alzheimer's patients are often not able to learn anymore because of their brain damage. **T** **F** (40)
27. Nutritional requirements for Alzheimer's patients are the same as for others of the same age and amount of activity. **T** **F** (41)
28. A possible explanation for Alzheimer's patients repetitive requests for food may be impairment in the normal appetite control center. **T** **F** (42)
29. Alzheimer's patients who step high over cracks or lines in the floor have a muscle control disturbance. **T** **F** (43)
30. There is always a continual decrease in sex drive from the early to the last stage of Alzheimer's disease. **T** **F** (44)
31. The loss of ability to recognize urge to defecate and/or urinate can be a reason for Alzheimer's patients' incontinence. **T** **F** (45)
32. Most drugs used to treat persons with Alzheimer's disease are used to increase the patient's comfort rather than to cure the disease. **T** **F** (46)
33. Chemical abnormalities in Alzheimer's disease are comparable in some ways to those in Parkinson's disease. **T** **F** (47)

The University of Iowa
College of Nursing
Alzheimer's Family Involvement in Care Study

Staff Perceptions of Caregiving Role (SPCR)

I.D.# _____
(Col. 4-9)

Date: _____
(Col. 10-13)

DIRECTIONS: Each of the statements in this questionnaire describes something about your role in the care of residents who have Alzheimer's Disease. You are asked to indicate your feelings about each statement in terms of the extent to which you agree or disagree. Please tell me the extent that you agree OR disagree with these statements. **A rating of 1 means that you "strongly disagree"; a rating of 7 means that you "strongly agree" with the statement.** Circle the number for each statement that best indicates the extent you agree or disagree.

We greatly appreciate your assistance with our study. **PLEASE TURN THE PAGE AND BEGIN.**

	STRONGLY DISAGREE							STRONGLY AGREE							Col.
1. I feel like some families' suggestions and requests interfere with staffs' abilities to care for the Alzheimer's residents.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	15
2. I feel like families should visit but leave the care of the Alzheimer's residents to the staff who are most familiar with their needs.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	16
3. I usually ask family members to leave the room when care is being provided for their relatives.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	17
4. A family member is usually included in decisions about the care of the Alzheimer's resident.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	18
5. Families need only give them information to staff about their relative's habits and preferences.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	19
6. The family member's role as caregiver is clearly secondary compared to staff after the relative is admitted to the nursing home.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	20
7. Most family members have control over the care their relatives receive.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	21
8. Most families would like to visit their relatives more often than staff want them to.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	22
9. Family members seem to be checking up on staff to see that care is delivered like they want it to be.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	23
10. Staff listen to family members' directions for their relatives' care but ignore the directions if they choose.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	24
11. It is clear that staff have the real say about what care will be provided and how.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	25
12. I feel like staff are there to help family members provide the best possible care for their relatives.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	26
13. The primary caregiving role of most family members has remained essentially unchanged since their relatives entered the nursing home.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	27
14. Although families don't provide all of their relative's care, most continue to be the primary caregivers.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	28
15. What families see as important in their relatives' care staff often see as not as important and too time consuming.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	29

	STRONGLY DISAGREE							STRONGLY AGREE							Col.
16. Staff are more concerned about policies and procedures in order to care for all of the residents, while family members are more concerned about caring for their relatives as individuals.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	30
17. Most families and staff agree that it is important for family members to be with their relatives as much as possible to participate in their care.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	31
18. Families and staff usually agree on the care priorities for the Alzheimer's residents.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	32
19. No major changes are made in the care of residents without family members' approval.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	33
20. Staff just want family members to be visitors, while family members want to be more involved in their relatives' care.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	34
21. I feel resentful of some family members who could but who do not do more things for their loved ones.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	35
22. I feel that the Alzheimer's residents often make requests that I perceive to be over and above what they need.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	36
23. I feel stressed between trying to provide care for residents with Alzheimer's as well as attend to other family and job responsibilities.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	37
24. I sometimes feel embarrassed over the Alzheimer's residents' behaviors.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	38
25. I feel guilty about some of my interactions with Alzheimer's residents.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	39
26. I feel that I don't do as much for the Alzheimer's residents as I could or should.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	40
27. I sometimes feel angry about my interactions with families.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	41
28. I feel nervous or depressed about my interactions with Alzheimer's residents.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	42
29. I feel that most families don't appreciate all that I do for the Alzheimer's residents.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	43
30. I feel that my stress from caring for Alzheimer's residents affects my relationships with my family members and friends in a negative way.	1	2	3	4	5	6	7	1	2	3	4	5	6	7	44

	STRONGLY DISAGREE			STRONGLY AGREE				Col.
31. I feel resentful about caring for Alzheimer's residents.	1	2	3	4	5	6	7	45
32. I feel the Alzheimer's residents are too dependent on staff.	1	2	3	4	5	6	7	46
33. I feel comfortable in my interactions with Alzheimer's residents.	1	2	3	4	5	6	7	47
34. I feel that my health has suffered because of my work with Alzheimer's residents.	1	2	3	4	5	6	7	48
35. I feel that Alzheimer's residents don't appreciate what I do for them as much as I would like.	1	2	3	4	5	6	7	49
36. I feel uncomfortable when families/friends visit their loved ones in the nursing home.	1	2	3	4	5	6	7	50
37. I feel that Alzheimer's residents often try to manipulate me.	1	2	3	4	5	6	7	51
38. I feel that some Alzheimer's residents expect me to take care of them as if I were the only one they could depend on.	1	2	3	4	5	6	7	52
39. I feel that there often are not enough resources to care for the Alzheimer's residents adequately.	1	2	3	4	5	6	7	53
40. I feel that more staff should be provided to care for Alzheimer's residents in nursing homes.	1	2	3	4	5	6	7	54
41. When family and staff have different ideas about care the disagreements are negotiated and resolved.	1	2	3	4	5	6	7	55
42. I feel that I can interact purposefully with families about the care of the residents with Alzheimer's.	1	2	3	4	5	6	7	56
43. I have mostly positive interactions with families.	1	2	3	4	5	6	7	57

Staff may feel sad because of the illness of the resident with Alzheimer's and the changes that the illness causes: To what extent do you agree or disagree that you feel **sad** over:

	(NOT AT ALL SAD)				(VERY SAD)				Col.
	STRONGLY DISAGREE				STRONGLY AGREE				
44. Inability to help the AD resident improve?	1	2	3	4	5	6	7	58	
45. Inability to help the family members cope with the deterioration of their loved one?	1	2	3	4	5	6	7	59	
46. Seeing AD patients lose the abilities that give them human dignity?	1	2	3	4	5	6	7	60	
47. Loss of meaningful interaction with residents?	1	2	3	4	5	6	7	61	
48. Inability to know what the Alzheimer's residents used to be like?	1	2	3	4	5	6	7	62	
49. The continued deterioration of the Alzheimer's residents?	1	2	3	4	5	6	7	63	
50. Lack of privacy for the Alzheimer's residents?	1	2	3	4	5	6	7	64	
51. Inability to control how the Alzheimer's residents are cared for?	1	2	3	4	5	6	7	65	
52. Loss of part of my role as primary caregiver of the Alzheimer's residents to the family members?	1	2	3	4	5	6	7	66	

Here are some thoughts and feeling that people sometimes have about themselves when they are caregivers of a relative who is ill. How much do you agree or disagree that each statement **describes your thoughts about your caregiving**?

	STRONGLY DISAGREE				STRONGLY AGREE				Col.
	1	2	3	4	5	6	7		
53. Wish you could care for AD residents like you can residents who are cognitively intact?	1	2	3	4	5	6	7	67	
54. Feel trapped by your inability to help the Alzheimer's resident?	1	2	3	4	5	6	7	68	
55. Wish you could transfer to a unit where there are no Alzheimer's residents?	1	2	3	4	5	6	7	69	
56. Wish you had more time to spend with other residents?	1	2	3	4	5	6	7	70	
57. Wish you could turn more of your caregiving role over to the family?	1	2	3	4	5	6	7	15	
58. Feel like AD residents really don't exist anymore as human personalities but still have to care for them as if they do?	1	2	3	4	5	6	7	16	

Hassles are irritants - things than annoy or bother you; it can make you upset or angry. Some hassles occur on a fairly regular basis and others are relatively rare. Some have only a slight effect, whereas others have a strong effect. Listed below are hassles that may occur in your day to day caregiving. You will find that during the past week some of these things will have been a hassle whereas others have not. For each item indicate the extent that you agree or disagree that the event was a hassle during the past week.

	STRONGLY DISAGREE				STRONGLY AGREE				Col.
59. Residents declining mentally.	1	2	3	4	5	6	7	17	
60. Assisting residents with walking.	1	2	3	4	5	6	7	18	
61. Assisting residents with grooming.	1	2	3	4	5	6	7	19	
62. Residents not showing interest in things.	1	2	3	4	5	6	7	20	
63. Assisting residents with bathing.	1	2	3	4	5	6	7	21	
64. Residents' agitation.	1	2	3	4	5	6	7	22	
65. Assisting residents eat or drink.	1	2	3	4	5	6	7	23	
66. Changes in residents' personalities.	1	2	3	4	5	6	7	24	
67. Assisting residents with exercise/therapy.	1	2	3	4	5	6	7	25	
68. Assisting residents with toileting.	1	2	3	4	5	6	7	26	
69. Residents' yelling/swearing.	1	2	3	4	5	6	7	27	
70. Residents not cooperating.	1	2	3	4	5	6	7	28	
71. Residents' forgetfulness.	1	2	3	4	5	6	7	29	
72. Residents being confused/not making sense.	1	2	3	4	5	6	7	30	
73. Residents asking repetitive questions.	1	2	3	4	5	6	7	31	
74. Residents not recognizing familiar people.	1	2	3	4	5	6	7	32	
75. Residents living in the past.	1	2	3	4	5	6	7	33	
76. Being in residents' presence.	1	2	3	4	5	6	7	34	
77. Residents talking about seeing things that aren't real.	1	2	3	4	5	6	7	35	
78. Helping residents dress.	1	2	3	4	5	6	7	36	

THANK YOU FOR FILLING OUT THE QUESTIONNAIRE!

The University of Iowa College of Nursing
Alzheimer's Family Involvement in Care Study

ATTITUDES ABOUT FAMILIES CHECKLIST

I.D.# _____
(4-9)

Date: _____
(10-13)

DIRECTIONS: Please rate each of the following items according to your most current observations and feelings about family members of Alzheimer's residents you work with. Circle the number that best indicates your opinion about your work with the residents and families.

Scale: Strongly disagree 1 2 3 4 5 6 7 Strongly agree

	<u>Strongly disagree</u>							<u>Strongly agree</u>			<u>Col.</u>
1. Most family members rarely come to see their relatives with Alzheimer's.	1	2	3	4	5	6	7				(15)
2. Most family members won't accept that their relatives with Alzheimer's are mentally incompetent.	1	2	3	4	5	6	7				(16)
3. Family members have too many requests that make my work more difficult.	1	2	3	4	5	6	7				(17)
4. Most family members know a lot about how to relate to their relatives with Alzheimer's.	1	2	3	4	5	6	7				(18)
5. Family members make too much noise and disturb other residents with Alzheimer's.	1	2	3	4	5	6	7				(19)
6. Family members often bring ideas that are helpful about how to care for their relatives.	1	2	3	4	5	6	7				(20)
7. Working with the family is an important part of my work.	1	2	3	4	5	6	7				(21)
8. It seems that when families come to the Alzheimer's unit, the residents get more agitated.	1	2	3	4	5	6	7				(22)
9. Family members are good about helping with the care of the residents with Alzheimer's.	1	2	3	4	5	6	7				(23)
10. When family members are on the Alzheimer's unit they seem to not know what to do.	1	2	3	4	5	6	7				(24)

	<u>Strongly</u> <u>disagree</u>						<u>Strongly</u> <u>agree</u>	<u>Col.</u>
11. Family members understand that we care for a number of residents with Alzheimer's and cannot always do the things they request.	1	2	3	4	5	6	7	(25)
12. Most residents with Alzheimer's ignore their families that are with them and don't seem to care if they are there or not.	1	2	3	4	5	6	7	(26)
13. Family members should have as much say as possible concerning the care of their relatives with Alzheimer's.	1	2	3	4	5	6	7	(27)
14. Family members should remember that they are visitors at the institution and should strictly follow our rules.	1	2	3	4	5	6	7	(28)
15. The institution's rules about family member visits should be more strict.	1	2	3	4	5	6	7	(29)
16. When families are with their relatives they often stay too long.	1	2	3	4	5	6	7	(30)

The University of Iowa College of Nursing
 Alzheimer's Family Involvement in Care Study

General Job Satisfaction Questionnaire (GJS)

I.D.# _____

Date: _____

DIRECTIONS:

Please rate the extent you agree with each of the following statements by circling the number on the scale directly opposite each statement.

Scale: Strongly disagree 1 2 3 4 5 6 7 Strongly agree

<u>Col.</u>	<u>Strongly Disagree</u>							<u>Strongly Agree</u>							
1. Generally speaking, I am satisfied with this job. (45)	1	2	3	4	5	6	7								
2. I frequently think of quitting this job. (46)	1	2	3	4	5	6	7								
3. I am generally satisfied with the kind of work I do (47) in this job.	1	2	3	4	5	6	7								