

FAMILY/CAREGIVER REPORT OF COGNITION

PATIENT'S NAME: _____ DATE: _____

YOUR NAME: _____ RELATIONSHIP: _____

When symptoms first noted: _____

First symptoms were: _____

Progression since the time (circle): Rapid Gradual Stepwise

Most problematic symptoms now: _____

Is there any family history of memory problems? _____

Does your loved one seem to have any of the following difficulties? If so, please check the box and give an example.

MEMORY

- Short term memory loss
- Long term memory loss
- Problems learning new things
- Forgetting friends
- Forgetting close family
- Misplacing/losing items
- Makes things up

LANGUAGE

- Repeating things
- Forgets word or uses wrong word
- Difficulty following story lines when watching TV/reading
- Difficulty following instructions

EXECUTIVE

- Loss of initiative
- Changes in planning, organizing, sequencing
- Errors with checkbook
- Errors with cooking or shopping
- Giving up previous activities
- Changes with familiar household tasks or hobbies
- Change in cleanliness of house
- Change in personal hygiene
- Trouble making decisions
- Judgement problems

VISUAL-SPATIAL

- Changes in writing/drawing
- Difficulty driving; recent accidents
- Disoriented or has erroneous concept of time
- Gets lost or has gotten lost in new places
- Gets lost or has gotten lost in familiar places
- Wanders

MOOD

- Apathy/Indifference
- Changes in Personality
- Anxiety/Nervousness
- Sadness/Depression/Tearfulness
- Switches mood suddenly (e.g. calm to upset)
- Fear of being alone or suspiciousness
- Delusions such as stealing, wanting to go home or "you're not my family"
- Hallucinations: visual, auditory, olfactory
- Sexually aggressive
- Agitation, verbal or physical

BEHAVIORS

- Pacing
- Purposeless activity
- Inappropriate activity
- Hitting, grabbing, pushing
- Restlessness
- Screaming
- Complaining
- Sundowning (becoming more confused in the evening)
- Reversal of sleep/wake cycles
- Leaves house at night
- Falling
- Incontinent

The Lawton Instrumental Activities of Daily Living Scale

A. Ability to Use Telephone

1. Operates telephone on own initiative; looks up and dials numbers..... 1
2. Dials a few well-known numbers..... 1
3. Answers telephone, but does not dial..... 1
4. Does not use telephone at all..... 0

B. Shopping

1. Takes care of all shopping needs independently..... 1
2. Shops independently for small purchases..... 0
3. Needs to be accompanied on any shopping trip..... 0
4. Completely unable to shop..... 0

C. Food Preparation

1. Plans, prepares, and serves adequate meals independently..... 1
2. Prepares adequate meals if supplied with ingredients..... 0
3. Heats and serves prepared meals or prepares meals but does not maintain adequate diet..... 0
4. Needs to have meals prepared and served..... 0

D. Housekeeping

1. Maintains house alone with occasion assistance (heavy work)..... 1
2. Performs light daily tasks such as dishwashing, bed making..... 1
3. Performs light daily tasks, but cannot maintain acceptable level of cleanliness..... 1
4. Needs help with all home maintenance tasks..... 1
5. Does not participate in any housekeeping tasks..... 0

E. Laundry

1. Does personal laundry completely..... 1
2. Launders small items, rinses socks, stockings, etc..... 1
3. All laundry must be done by others..... 0

F. Mode of Transportation

1. Travels independently on public transportation or drives own car..... 1
2. Arranges own travel via taxi, but does not otherwise use public transportation..... 1
3. Travels on public transportation when assisted or accompanied by another..... 1
4. Travel limited to taxi or automobile with assistance of another..... 0
5. Does not travel at all..... 0

G. Responsibility for Own Medications

1. Is responsible for taking medication in correct dosages at correct time..... 1
2. Takes responsibility if medication is prepared in advance in separate dosages..... 0
3. Is not capable of dispensing own medication..... 0

H. Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); collects and keeps track of income..... 1
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc..... 1
3. Incapable of handling money..... 0

Scoring: For each category, circle the item description that most closely resembles the client's highest functional level (either 0 or 1).

Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9(3), 179-186.

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Katz Index of Independence in Activities of Daily Living

Activities Points (1 or 0 points)	Independence (1 point) No supervision, direction or personal assistance	Dependence (0 points) With supervision, direction, personal assistance or total care
Bathing _____	Bathes self completely or needs help in bathing only a single part of the body, such as the back, genital area or disabled extremity	Needs help with bathing more than one part of the body, getting in or out of the bathtub or shower; requires total bathing
Dressing _____	Gets clothes from closets and drawers, and puts on clothes and outer garments complete with fasteners; may need help tying shoes	Needs help with dressing self or needs to be completely dressed
Toileting _____	Goes to toilet, gets on and off, arranges clothes, cleans genital area without help	Needs help transferring to the toilet and cleaning self, or uses bedpan or commode
Transferring _____	Moves in and out of bed or chair unassisted; mechanical transfer aids (cane or walker) are acceptable	Needs help in moving from bed to chair or requires a complete transfer
Fecal/Urinary continence _____	Exercises complete control over urination and defecation	Is partially or totally incontinent of bowel or bladder (accidents or leaking)
Feeding _____	Gets food from plate into mouth without help; preparation of food may be done by another person	Needs partial or total help with feeding or requires parenteral (g-tube) feeding

Total _____

Adapted from Katz, S. Downs, TD, Cash HR, Grotz, RC. Progress in development of the index of ADL. Gerontologist. 1970; 10(1):23.

Zarit Caregiver Burden Scale

Caregiver's Name: _____

Date: _____

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way; never, rarely, sometimes, frequently or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0	1	2	3	4
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Symptoms of Early Dementia-11 Questionnaire (SED-11Q)

Patient's Name: _____

Date: _____

Your Name: _____

Relationship: _____

How has the patient's daily life been for the last month? Please answer the following questions by circling the appropriate responses: Yes, No, N/A (not applicable), DK (don't know). Exclude any difficulties caused by physical issues e.g. pain. Please ask for any help if needed.

	Yes	No	N/A	DK
He/she talks and asks about the same things repeatedly.				
He/she has been unable to understand the context of facts				
He/she has become indifferent about clothing and other personal concerns.				
He/she has begun to forget to turn off the faucet and/or close the door; and/or has become unable to clean up properly.				
When doing two things at the same time, he/she forgets one of them.				
He/she has become unable to take medication under proper management.				
He/she has begun to take a longer time to do work (e.g. household chores) which could be done quickly before.				
He/she has become unable to make a plan.				
He/she cannot understand complex topics.				
He/she has become less interested and willing, and stopped hobbies, etc.				
He/she has become more irritable and suspicious than before.				
He/she has delusions, e.g. claims to have had valuables stolen.				
He/she has illusions, e.g., sees something that isn't there.				

Neuropsychiatric Inventory Questionnaire

Name of patient: _____ Date: _____

Informant: Spouse: _____ Child: _____ Other: _____

Please answer the following questions based on *changes* that have occurred since the patient first began to experience memory problems.

Circle "yes" only if the symptom has been present in the *past month*. Otherwise, circle "no".

For each item marked "yes":

Rate the *severity* of the symptom (how it affects the patient):

1 = Mild (noticeable, but not a significant change)

2 = Moderate (significant, but not a dramatic change)

3 = Severe (very marked or prominent; a dramatic change)

Rate the *distress* you experience because of that symptom (how it affects you):

0 = Not distressing at all

1 = Minimal (slightly distressing, not a problem to cope with)

2 = Mild (not very distressing, generally easy to cope with)

3 = Moderate (fairly distressing, not always easy to cope with)

4 = Severe (very distressing, difficult to cope with)

5 = Extreme or very severe (extremely distressing, unable to cope with)

Please answer each question honestly and carefully. Ask for assistance if you are not sure how to answer any question.

Delusions	Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Hallucinations	Does the patient act as if he or she hears voices? Does he or she talk to people who are not there?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Agitation or aggression	Is the patient stubborn and resistive to help from others?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Depression or dysphoria	Does the patient act as if he or she is sad or in low spirits? Does he or she cry?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Anxiety	Does the patient become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Elation or euphoria	Does the patient appear to feel too good or act excessively happy?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Apathy or indifference	Does the patient seem less interested in his or her usual activities and in the activities and plans of others?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Disinhibition	Does the patient seem to act impulsively? For example, does the patient talk to strangers as if he or she knows them, or does the patient say things that may hurt people's feelings?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Irritability or lability	Is the patient impatient and cranky? Does he or she have difficulty coping with delays or waiting for planned activities?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Motor disturbance	Does the patient engage in repetitive activities, such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Nighttime behaviors	Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Appetite and eating	Has the patient lost or gained weight, or had a change in the food he or she likes?	
Yes No	Severity: 1 2 3	Distress: 0 1 2 3 4 5

FIGURE 3. Neuropsychiatric Inventory Questionnaire. This tool provides a reliable assessment of behaviors commonly observed in patients with dementia.

Patient Resources for Dementia

Websites

- Alzheimer's Association (<https://www.alz.org/>)
- Alzheimer's Society Canada (<http://alzheimer.ca/en/Home>)
- Dementia Australia (<https://www.dementia.org.au/>)
- Alzheimer's Society (<https://www.alzheimers.org.uk/>)
- UCSF's Tips for Daily Life (<https://memory.ucsf.edu/tips-daily-life>)

Recommended Publications

- <https://order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide> (free)
- **Alzheimer's Early Stages: First Steps for Family, Friends, and Caregivers, 3rd edition by Daniel Kuhn (~\$17)**