

# COGNITIVE IMPAIRMENT CARE PLANNING TOOLKIT

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A guide to conducting a reimbursable clinical visit under CPT® code 99483



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TABLE OF CONTENTS

Cognitive Assessment and Care Planning Services: Alzheimer’s Association®  
Expert Task Force Recommendations and Tools for Implementation .....2

Mini-Cog© .....9

General Practitioner Assessment of Cognition (GPCOG) ..... 11

Montreal Cognitive Assessment (MoCA)..... 14

Functional Activities Questionnaire (FAQ) ..... 21

Katz Index of Independence in Activities of Daily Living (ADL) ..... 23

Lawton-Brody Instrumental Activities of Daily Living Scale (IADL) ..... 25

Dementia Severity Rating Scale (DSRS) ..... 27

The Neuropsychiatric Inventory Questionnaire (NPI-Q) ..... 31

BEHAV5+ ..... 37

Patient Health Questionnaire-2 (PHQ-2) ..... 38

Medication List for Review ..... 39

Safety Assessment ..... 40

Caregiver Profile ..... 47

Stress Thermometer..... 48

End-of-Life Checklist ..... 49

Patient and Caregiver Resources ..... 50

### **1. Background and introduction to CPT® code 99483**

The Alzheimer's Association® has long advocated for Medicare reimbursement for services aimed at improving detection, diagnosis, and care planning and coordination for patients with Alzheimer's disease and related dementias (ADRD) and their caregivers (Attea, Johns, 2010). These efforts, embodied in the Health Outcomes, Planning, and Education for Alzheimer's (HOPE) Act and aided by support from physician groups involved in developing new Current Procedural Terminology (CPT) codes, culminated in approval of a Medicare procedure code, G0505, which took effect January 1, 2017. In January 2018, G0505 was replaced by CPT code 99483. Code 99483 provides reimbursement to physicians and other eligible billing practitioners for a comprehensive clinical visit that results in a written care plan. Code 99483 requires an independent historian; a multidimensional assessment that includes cognition, function, and safety; evaluation of neuropsychiatric and behavioral symptoms; review and reconciliation of medications; and assessment of the needs of the patient's caregiver. (See the CPT 2018 manual for full details.) These components are central to informing, designing and delivering a care plan suitable for patients with cognitive impairment (Anonymous. Fed Register 2016).

The Alzheimer's Association Expert Task Force provided information and suggestions on the content and use of Code G0505 (now 99483) to the Centers for Medicare & Medicaid (CMS) during the comment phase (Alzheimer's Association Task Force, 2016), and reconvened in November 2016 to make recommendations about how to conduct the required assessments. Its recommendations derive from a broad consensus about good clinical practice, informed by intervention trials and emphasizing validated assessment tools that can be implemented in routine clinical care across the United States. The multidisciplinary task force was comprised of geographically dispersed experts in the United States who provide ongoing clinical care for individuals with ADRD and/or have published recognized works in the field.

### **2. Who is eligible to receive this comprehensive care planning service?**

Cognitive assessment and care plan services are provided when a comprehensive evaluation of a new or existing patient, who exhibits signs and/or symptoms of cognitive impairment, is required to establish or confirm a diagnosis, etiology and severity for the condition.

Do not report cognitive assessment and care plan services if any of the required elements are not performed or are deemed unnecessary for the patient's condition. For these services, see the appropriate evaluation and management (E/M) code. (American Medical Association, CPT 2018).

### **3. Who can provide this service?**

Any practitioner eligible to report E/M services can provide this service. Eligible providers include physicians (MD and DO), nurse practitioners, clinical nurse specialists, and physician assistants. Eligible practitioners must provide documentation that supports a moderate-to-high level of complexity in medical decision making, as defined by E/M guidelines (with application as appropriate of the usual "incident-to" rules, consistent with other E/M services) (Anonymous. Fed Register 2016). The provider must also document the detailed care plan developed as a result of each required element covered by 99483.

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#### 4. What must the clinician do to meet the required elements for code 99483?

Assessment of and care planning for a patient with cognitive impairment, requiring an independent historian, in the office or other outpatient, home, domiciliary or rest home setting with all of the following required elements:

- Cognition-focused evaluation including a pertinent history and examination;
- Medical decision-making of moderate or high complexity;
- Functional assessment (e.g., basic and instrumental activities of daily living), including decision-making capacity;
- Use of standardized instruments for staging of dementia (e.g., functional assessment staging test [FAST], clinical dementia rating [CDR]);
- Medication reconciliation and review for high-risk medications;
- Evaluation for neuropsychiatric and behavioral symptoms, including depression, including use of standardized screening instrument(s);
- Evaluation of safety (e.g., home), including motor vehicle operation;
- Identification of caregiver(s), caregiver knowledge, caregiver needs, social supports and the willingness of caregiver to take on caregiving tasks;
- Development, updating or revision, or review of an Advance Care Plan;
- Creation of a written care plan, including initial plans to address any neuropsychiatric symptoms, neurocognitive symptoms, functional limitations and referral to community resources as needed (e.g., rehabilitation services, adult day programs, support groups) shared with the patient and/or caregiver with initial education and support.

Typically, 60 minutes are spent face to face with the patient and/or family or caregiver.

***See the 2021 CPT manual for the full description and detailed instructions for code 99483.***

#### 5. When, where and by whom can the required elements be assessed?

The nine assessment elements of 99483 can be evaluated within the care planning visit or in one or more visits that precede it, using appropriate billing codes (most often an E/M code). Patients with complex medical, behavioral, psychosocial and/or caregiving needs may require a series of assessment visits, while those with well-defined or less complex problems may be fully assessed during the care plan visit. Results of assessments conducted prior to the care plan visit are allowed in care planning documentation provided they remain valid or are updated with any changes at the time of care planning.

A single physician or other qualified health care professional should not report 99483 more than once every 180 days.

Many of the required assessment elements can be completed by appropriately trained members of the clinical team working with the eligible provider. Assessments that require the direct participation of a knowledgeable care partner or caregiver, such as a structured assessment of the patient's functioning at home or a caregiver stress measure, may be completed prior to the clinical visit and provided to the clinician for inclusion in care planning. Care planning visits can be conducted in the office or other outpatient, home, domiciliary or rest home settings.

#### 6. What measurement tools should be used to support the care planning process and its documentation?

Standardized, validated tools are preferred whenever possible and are required for some elements (see Table 1 for suggested tools). Such tools offer a basic framework on which to build a nuanced clinical understanding of care needs through ongoing clinical contact with the patient and caregiver. Though all required elements must be represented, the choice of assessment tools should be customized for differing clinician styles and practice composition, workflows and overall clinical goals. For example, primary care providers and dementia specialists may prefer different tools.

For several domains of care planning, simple, validated tools do not yet exist. This is most evident in primary care settings for cognitive assessment. In the table below, refer to the comments section for details on assessment administration and validity in various care settings for cognition-based tools. Ideally, tools should be:

- **Practical:** Time and effort to complete them fit the primary care clinical setting.
- **Parsimonious:** Provide enough information to support a meaningful care plan.
- **Scorable:** Results depicted in a single number.
- **Retrievable:** Easily incorporated into electronic health record fields and searchable at the point of care.

**Table 1: Suggested Measures to Support the Care-Planning Process**

The table below provides examples of simpler and more complex tools acceptable for assessing each domain. In some settings, a simple tool might be sufficient; in others, it could be used to trigger a more complex assessment or be replaced by a more detailed measure.

Domain	Suggested measures	Comments
<b>Cognition</b>	Mini-Cog©	≤ 5 min, validated in community and general practice samples
	GPCOG	Brief, patient/informant components, validated in community and general practice samples
	MoCA	10-15 mins, validated in memory clinics, higher sensitivity and specificity for Mild Cognitive Impairment (MCI)
<b>Function</b>	Katz (ADL), Lawton-Brody (IADL) FAQ Test	Caregiver rated
<b>Stage of cognitive impairment</b>	Dementia Severity Rating Scale (DSRS)	Caregiver rated, correlates with Clinical Dementia Rating
<b>Neuropsychiatric symptoms</b>	NPI-Q	10 items
<b>Depression</b>	BEHAVE 5+ PHQ-2	6 high-impact items Depression identification
<b>Medication review and reconciliation</b>	Med list + name of person overseeing home meds	Identify/reconsider high-risk meds; assess for reliable administration by self or other
<b>Safety</b>	Safety Assessment Guide	7 questions (patient/caregiver)
<b>Caregiver identification and needs assessment</b>	Caregiver Profile Checklist PHQ-2	Ability/willingness to care, needs for information, education, and support Depression identification
<b>Advance care planning</b>	End-of-Life Checklist	Screen for preferences and legal needs



## 7. The written care plan

### Preparing the plan

The care plan should reflect a synthesis of the information acquired as part of the assessment. It should be written in language that is easily understood, indicate who has responsibility for carrying out each recommended action step and specify an initial follow-up schedule.

Some clinicians find it useful to organize the care plan into broad components, such as:

- Specific characteristics of the cognitive disorder (e.g., type and severity of cognitive impairment; special hazards such as falls or orthostatic hypotension in Lewy body dementia; or referral to a dementia specialist for further diagnostic assessment or complex management).
- Management of any neuropsychiatric symptoms, including referrals for caregiver stress and behavior management training or psychiatric care for the patient as indicated.
- Comorbid medical conditions and safety management, including any changes needed to accommodate the effects of cognitive impairment.
- Caregiver stress and support needs, including primary care counseling and, as indicated, referrals to community-based education and support, specialized individual or family counseling, or in-home care, legal or financial assistance.

### Documenting and sharing the plan

Though not required by 99483, a standardized care plan template customized to the provider or health care system simplifies communication and tracking of patient care and outcomes over time. The written plan must be discussed with and given to the patient and/or family or caregiver; this face-to-face conversation must be documented in the clinical note for all encounters reported using 99483. The care plan must be filed in the patient's medical record where it can be easily retrieved and updated. Sharing the plan with other providers caring for the patient, including clinicians, care managers, caseworkers and others who assist the patient and caregiver, both within and outside the primary care environment, will help ensure continuity and coordination of care. When such sharing requires explicit consent of the patient, family caregiver or legally designated decision-maker (DPOA holder), that permission should be sought and documented.

## 8. How often can 99483 be used?

Qualified health care professionals may report 99483 as frequently as once per 180 days, per CPT. However, payer policy may say otherwise and should be consulted. Care plans should be revised at intervals and whenever there is a change in the patient's clinical or caregiving status. Medicare intermediaries may audit the frequency of use.

## 9. How does 99483 relate to Chronic Care Management (CPT 99490)?

CPT code 99490 is an appropriate service to use for monthly care management of a patient with dementia plus at least one other chronic condition, after a cognitive impairment care plan has been developed and documented.

## 10. Identifying proper coding

CPT code 99483 was developed to provide reimbursement for comprehensive evaluation of a new or existing patient who exhibits signs and/or symptoms of cognitive impairment when required to establish or confirm a diagnosis, etiology and severity for the condition. This service includes a thorough evaluation of medical and psychosocial factors, potentially contributing to increased morbidity. Do not report cognitive assessment and care plan services if any of the required elements are not performed or are deemed unnecessary for the patient's condition. For these services, see the appropriate evaluation and management code.

**Table 2: Commonly used ICD-10 codes for dementia and mild cognitive impairment**

Code	Description
G300	Dementia Alzheimer's disease with early-onset
G301	Dementia Alzheimer's disease with late-onset
G309	Dementia Alzheimer's disease, unspecified
F01.50	Vascular dementia without behavioral disturbance
F01.51	Vascular dementia with behavioral disturbance
F02.80	Dementia in other diseases classified elsewhere without behavioral disturbance
F02.81	Dementia in other diseases classified elsewhere with behavioral disturbance
F03.90	Unspecified dementia without behavioral disturbance
F03.91	Unspecified dementia with behavioral disturbance
G31.01	Pick's disease
G31.09	Other frontotemporal dementia
G31.85	Corticobasal degeneration
G31.83	Dementia with Lewy bodies
G31.84	Mild cognitive impairment, so stated

**Table 3: CPT codes that cannot be reported in conjunction with 99483**

Because many 99483 elements overlap with other CPT codes, CMS provides specific guidelines on which CPT codes cannot be reported together with 99483 on the same date of service. It is important to note that Medicare Advantage Plans and Accountable Care Organizations may have different reimbursement criteria. Payer policy should be consulted.

Code	Description
90785	Psychotherapy complex interactive
90791	Psychiatric diagnostic evaluation
90792	Psychiatric diagnostic evaluation with medical services
96103	Psychological testing administered by a computer
96120	Neuropsychological testing administered with a computer
96127	Brief emotional/behavioral assessment
96160-96161	Health risk assessment administration
99201-99215	Office/outpatient visits new patient
99241-99245	New or established patient office or outpatient consultation services
99324-99337	Domicile/rest home visits new patient
99341-99350	Home visits new patient
99366-99368	Team conference with patient by healthcare professional
99497	Advanced care plan 30 min
99498	Advanced care plan additional 30 min
99605-99607	Medication therapy management services
G0506	Comprehensive assessment of and care planning by the billing practitioner for patients requiring CCM services
G0181, G0182	Home health care and hospice supervision

**Table 4: CPT codes that can be reported with 99483 on the same date of service**

CMS does not believe the services described in 99483 would significantly overlap with the following codes.

Code	Description
99358, 99359	Non-face-to-face prolonged services
99487, 99489, 99490	Chronic care management (CCM) services
99495, 99496	Transitional care management (TCM) services
G2212	Prolonged office/outpatient E/M services



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### Step 1: Three Word Registration

Look directly at person and say, "Please listen carefully. I am going to say three words that I want you to repeat back to me now and try to remember. The words are [select a list of words from the versions below]. Please say them for me now." If the person is unable to repeat the words after three attempts, move on to Step 2 (clock drawing).

The following and other word lists have been used in one or more clinical studies.<sup>1-3</sup> For repeated administrations, use of an alternative word list is recommended.

Version 1	Version 2	Version 3	Version 4	Version 5	Version 6
Banana	Leader	Village	River	Captain	Daughter
Sunrise	Season	Kitchen	Nation	Garden	Heaven
Chair	Table	Baby	Finger	Picture	Mountain

### Step 2: Clock Drawing

Say: "Next, I want you to draw a clock for me. First, put in all of the numbers where they go." When that is completed, say: "Now, set the hands to 10 past 11."

Use preprinted circle (see next page) for this exercise. Repeat instructions as needed as this is not a memory test. Move to Step 3 if the clock is not complete within three minutes.

### Step 3: Three Word Recall

Ask the person to recall the three words you stated in Step 1. Say: "What were the three words I asked you to remember?" Record the word list version number and the person's answers below.

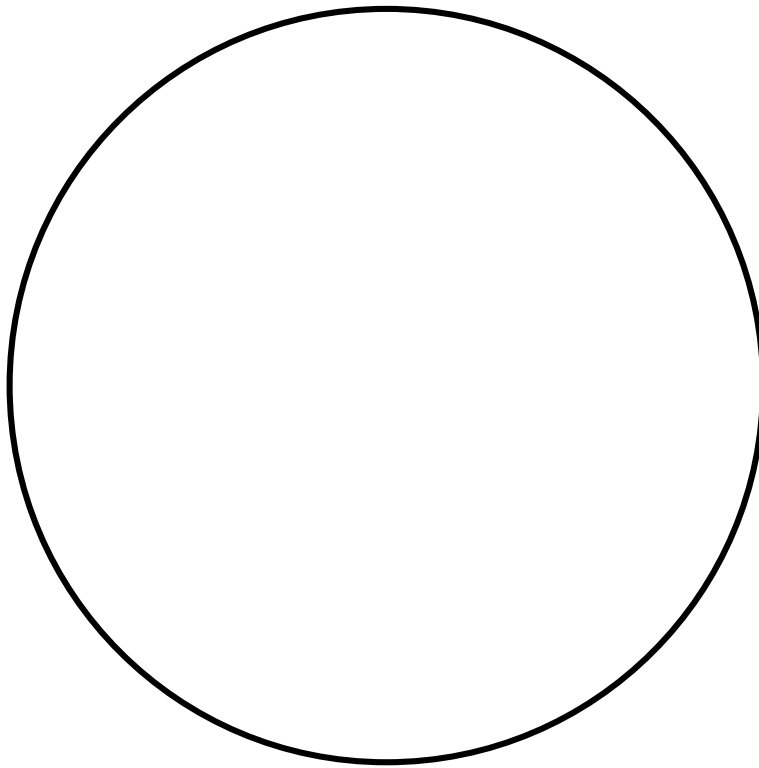
Word List Version: \_\_\_\_\_ Person's Answers: \_\_\_\_\_

### Scoring

Word Recall: _____ (0-3 points)	1 point for each word spontaneously recalled without cueing.
Clock Draw: _____ (0 or 2 points)	Normal clock = 2 points. A normal clock has all numbers placed in the correct sequence and approximately correct position (e.g., 12, 3, 6 and 9 are in anchor positions) with no missing or duplicate numbers. Hands are pointing to the 11 and 2 (11:10). Hand length is not scored. Inability or refusal to draw a clock (abnormal) = 0 points.
Total Score: _____ (0-5 points)	Total score = Word Recall score + Clock Draw score.  A cut point of <3 on the Mini-Cog™ has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended as it may indicate a need for further evaluation of cognitive status.

## Clock Drawing

ID:\_\_\_\_\_ Date:\_\_\_\_\_



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## GENERAL PRACTITIONER ASSESSMENT OF COGNITION (GPCOG)

A web-based GPCOG and downloadable paper-and-pencil versions of the GPCOG (in many languages) are available at [gpcog.com.au](http://gpcog.com.au). Both ask the same questions, the only difference being the web-based GPCOG automatically scores the test.

### Preparation & Training

Before you administer GPCOG for the first time, please review the following:

1. Make sure you have read the instructions (on the first page of the test)
2. Watch the training video (approx. 5 minutes)

[https://www.youtube.com/watch?v=lf7nv2\\_B89M](https://www.youtube.com/watch?v=lf7nv2_B89M)

Patient name: \_\_\_\_\_

Testing date: \_\_\_\_\_



## STEP 1 – PATIENT EXAMINATION

Unless specified, each question should only be asked once.

### Name and address for subsequent recall test

*I am going to give you a name and address. After I have said it, I want you to repeat it. Remember this name and address because I am going to ask you to tell it to me again in a few minutes: John Brown, 42 West Street, Kensington. (Allow a maximum of 4 attempts.)*

### Time orientation

1. *What is the date?* (exact only)

**Correct**    **Incorrect**

☐
☐

### Clock drawing (use blank page)

2. *Please mark in all the numbers to indicate the hours of a clock.* (correct spacing required)
3. *Please mark in hands to show 10 minutes past eleven o'clock.* (11.10)

☐
☐
☐
☐

### Information

4. *Can you tell me something that happened in the news recently?* (Recently = in the last week. If a general answer is given, e.g. "war", "lot of rain", ask for details. Only specific answer scores.)

☐
☐

### Recall

5. *What was the name and address I asked you to remember?*

John

Brown

42

West (St)

Kensington

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

Add the number of items answered correctly:

**Total score:**

☐

**out of 9**

### 9 No significant cognitive impairment

Further testing is not necessary

### 5 – 8 More information required

Proceed with informant interview in step 2 on next page

### 0 – 4 Cognitive impairment is indicated

Conduct standard investigations

Patient name: \_\_\_\_\_

Testing date: \_\_\_\_\_



## STEP 2: INFORMANT INTERVIEW

Informant name: \_\_\_\_\_

Relationship to patient, i.e. informant is the patient's: \_\_\_\_\_

Ask the informant:

*Compared to 5–10 years ago,*1. *Does the patient have more trouble remembering things that have happened recently than s/he used to?*

YES NO Don't know N/A

☐ ☐ ☐
2. *Does s/he have more trouble recalling conversations a few days later?*
☐ ☐ ☐
3. *When speaking, does s/he have more difficulty in finding the right word or tend to use the wrong words more often?*
☐ ☐ ☐
4. *Is s/he less able to manage money and financial affairs (e.g. paying bills and budgeting)?*
☐ ☐ ☐ ☐
5. *Is s/he less able to manage his or her medication independently?*
☐ ☐ ☐ ☐
6. *Does s/he need more assistance with transport (either private or public)?*  
(If the patient has difficulties only due to physical problems, e.g. bad leg, tick 'no'.)
☐ ☐ ☐ ☐

Add the number of items answered with 'NO', 'Don't know' or 'N/A':

Total score: ☐ out of 6**4 – 6 No significant cognitive impairment**

Further testing is not necessary

**0 – 3 Cognitive impairment is indicated**

Conduct standard investigations

When referring to a specialist, mention the individual scores for the two GPCOG test steps:

STEP 1 Patient examination: \_\_\_\_ / 9

STEP 2 Informant interview: \_\_\_\_ / 6 or N/A



Downloadable copies of the MoCA test (in many languages) and administration and scoring instructions are available at no charge at [mocatest.org](http://mocatest.org). Training and certification are required for accuracy.

1. Visit [mocatest.org](https://mocatest.org) and register for a free account. You will need to complete the form that appears and submit. A confirmation email will be sent to you with a link to complete the registration.

2. Once you have clicked on the confirmation link in your email, you may proceed to use the MoCA test.

3. Select the appropriate test version and language desired.

4. Download the test form. A sample of tasks for version 8.3 follows.

**www.mocatest.org**

Name:

**Education:**

**Sex:**

**Date of birth :**

DATE : \_\_\_\_\_

<b>MEMORY</b> Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.		LEG	COTTON	SCHOOL	TOMATO	WHITE	<b>NO POINTS</b>
	1st TRIAL						
	2nd TRIAL						

<b>DELAYED RECALL</b>	(MIS)	Has to recall words	LEG	COTTON	SCHOOL	TOMATO	WHITE	Points for UNCUED recall only	<b>___/5</b>
Memory Index Score (MIS)	X3	WITH NO CUE	[ ]	[ ]	[ ]	[ ]	[ ]		
	X2	Category cue						MIS = ___/15	
	X1	Multiple choice cue							

VISUOSPATIAL / EXECUTIVE		DRAWING		
<p>A dot-marker task diagram. It consists of eight points arranged in a roughly circular pattern: 1 at the top, 2 at the top-right, 3 at the bottom-right, 4 at the bottom-left, 5 at the left, 6 at the top-left, A at the top-right, and B at the top. The path starts at point 1, goes to A, then to 2, then to B, then to C, then to D, then to E, and finally back to 1. Arrows indicate the direction of the path.</p>		<p>Copy bed</p> <p>A simple line drawing of a bed frame, consisting of two parallel horizontal lines representing the headboard and footboard, connected by four vertical lines representing the legs.</p>		
<p>Begin</p>		<p>Draw CLOCK (Five past ten)</p>		
<p>End</p>				
[ ]	[ ]	[ ]	[ ]	[ ]
Contour	Numbers	Hands		

ATTENTION	Read list of digits (1 digit/sec.).	Subject has to repeat them in the forward order.	[ ] 2 4 8 1 5	___/2		
		Subject has to repeat them in the backward order.	[ ] 4 2 7			
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors.				___/1		
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B						
Serial 7 subtraction starting at 60.	[ ] 53	[ ] 46	[ ] 39	[ ] 32	[ ] 25	___/3
4 or 5 correct subtractions: <b>3 pts,</b> 2 or 3 correct: <b>2 pts,</b> 1 correct: <b>1 pt,</b> 0 correct: <b>0 pt</b>						

## Montreal Cognitive Assessment (MoCA) Version 8.3

### Administration and Scoring Instructions

The Montreal Cognitive Assessment (MoCA) was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. The MoCA may be administered by anyone who understands and follows the instructions, however, only a health professional with expertise in the cognitive field may interpret the results. Time to administer the MoCA is approximately 10 minutes. The total possible score is 30 points; a score of 26 or above is considered normal.

All instructions may be repeated once.

#### 1. Alternating Trail Making:

Administration: The examiner instructs the subject: *"Please draw a line going from a number to a letter in ascending order. Begin here [point to (1)] and draw a line from 1 then to A then to 2 and so on. End here [point to (E)]."*

Scoring: One point is allocated if the subject successfully draws the following pattern: 1- A- 2- B- 3- C- 4- D- 5- E, without drawing any lines that cross. Any error that is not immediately self-corrected (meaning corrected before moving on to the Bed task) earns a score of 0. A point is not allocated if the subject draws a line to connect the end (E) to the beginning (1).

#### 2. Visuoconstructional Skills (Bed):

Administration: The examiner gives the following instructions, pointing to the bed: *"Copy this drawing as accurately as you can."*

Scoring: One point is allocated for a correctly executed drawing.

- Drawing must be three-dimensional.
- All lines are drawn.
- All lines meet with little or no space.
- No line is added.
- Lines are relatively parallel and their length is similar.
- The bed's orientation in space must be preserved.

A point is not assigned if any of the above criteria is not met.

#### 3. Visuoconstructional Skills (Clock):

Administration: The examiner must ensure that the subject does not look at his/her watch while performing the task and that no clocks are in sight. The examiner indicates the appropriate space and gives the following instructions: *"Draw a clock. Put in all the numbers and set the time to 5 past 10."*

Scoring: One point is allocated for each of the following three criteria:

- Contour (1 pt.): the clock contour must be drawn (either a circle or a square). Only minor distortions are acceptable (e.g., slight imperfection on closing the circle). If the numbers are arranged in a circular manner but the contour is not drawn the contour is scored as incorrect.
- Numbers (1 pt.): all clock numbers must be present with no additional numbers. Numbers must be in the correct order, upright and placed in the approximate quadrants on the clock face. Roman numerals are acceptable. The numbers must be arranged in a circular manner (even if the contour is a square). All numbers must either be placed inside or outside the clock contour. If the subject places some numbers inside the clock contour and some outside the clock contour, (s)he does not receive a point for Numbers.
- Hands (1 pt.): there must be two hands jointly indicating the correct time. The hour hand must be clearly shorter than the minute hand. Hands must be centered within the clock face with their junction close to the clock center.

#### 4. **Naming:**

Administration: Beginning on the left, the examiner points to each figure and says: *“Tell me the name of this animal.”*

Scoring: One point is given for each of the following responses: (1) horse, pony, mare or foal (2) tiger (3) duck.

#### 5. **Memory:**

Administration: The examiner reads a list of five words at a rate of one per second, giving the following instructions: *“This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn’t matter in what order you say them.”* The examiner marks a check in the allocated space for each word the subject produces on this first trial. The examiner may not correct the subject if (s)he recalls a deformed word or a word that sounds like the target word. When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, the examiner reads the list a second time with the following instructions: *“I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time.”* The examiner puts a check in the allocated space for each word the subject recalls on the second trial. At the end of the second trial, the examiner informs the subject that (s)he will be asked to recall these words again by saying: *“I will ask you to recall those words again at the end of the test.”*

Scoring: No points are given for Trials One and Two.

#### 6. **Attention:**

Forward Digit Span: Administration: The examiner gives the following instructions: *“I am going to say some numbers and when I am through, repeat them to me exactly as I said them.”* The examiner reads the five number sequence at a rate of one digit per second.

Backward Digit Span: Administration: The examiner gives the following instructions: *“Now I am going to say some more numbers, but when I am through you must repeat them to me in the backward order.”* The examiner reads the three number sequence at a

rate of one digit per second. If the subject repeats the sequence in the forward order, the examiner may not ask the subject to repeat the sequence in backward order at this point.

Scoring: One point is allocated for each sequence correctly repeated (N.B.: the correct response for the backward trial is 7-2-4).

Vigilance: Administration: The examiner reads the list of letters at a rate of one per second, after giving the following instructions: *“I am going to read a sequence of letters. Every time I say the letter A, tap your hand once. If I say a different letter, do not tap your hand.”*

Scoring: One point is allocated if there is zero to one error (an error is a tap on a wrong letter or a failure to tap on letter A).

Serial 7s: Administration: The examiner gives the following instructions: *“Now, I will ask you to count by subtracting 7 from 60, and then, keep subtracting 7 from your answer until I tell you to stop.”* The subject must perform a mental calculation, therefore, (s)he may not use his/her fingers nor a pencil and paper to execute the task. The examiner may not repeat the subject’s answers. If the subject asks what her/his last given answer was or what number (s)he must subtract from his/her answer, the examiner responds by repeating the instructions if not already done so.

Scoring: This item is scored out of 3 points. Give no (0) points for no correct subtractions, 1 point for one correct subtraction, 2 points for two or three correct subtractions, and 3 points if the subject successfully makes four or five correct subtractions. Each subtraction is evaluated independently; that is, if the subject responds with an incorrect number but continues to correctly subtract 7 from it, each correct subtraction is counted. For example, a subject may respond “52 - 45 - 38 - 31 - 24” where the “52” is incorrect, but all subsequent numbers are subtracted correctly. This is one error and the task would be given a score of 3.

## 7. Sentence repetition:

Administration: The examiner gives the following instructions: *“I am going to read you a sentence. Repeat it after me, exactly as I say it [pause]: **The child walked his dog in the park after midnight.**”* Following the response, say: *“Now I am going to read you another sentence. Repeat it after me, exactly as I say it [pause]: **The artist finished his painting at the right moment for the exhibition.**”*

Scoring: One point is allocated for each sentence correctly repeated. Repetitions must be exact. Be alert for omissions (e.g., omitting “right”), substitutions/additions (e.g., substituting “after” for “at”), grammar errors/altering plurals (e.g. “his painting” for “his paintings”), etc.

## 8. Verbal fluency:

Administration: The examiner gives the following instructions: *“Now, I want you to tell me as many words as you can think of that begin with the letter B. I will tell you to stop after one minute. Proper nouns, numbers, and different forms of a verb are not permitted. Are you ready? [Pause] [Time for 60 sec.] Stop.”* If the subject names two consecutive

words that begin with another letter of the alphabet, the examiner repeats the target letter if the instructions have not yet been repeated.

**Scoring:** One point is allocated if the subject generates 11 words or more in 60 seconds. The examiner records the subject's responses in the margins or on the back of the test sheet.

## 9. **Abstraction:**

**Administration:** The examiner asks the subject to explain what each pair of words has in common, starting with the example: *"I will give you two words and I would like you to tell me to what category they belong to [pause]: an orange and a banana."* If the subject responds correctly the examiner replies: *"Yes, both items are part of the category Fruits."* If the subject answers in a concrete manner, the examiner gives one additional prompt: *"Tell me another category to which these items belong to."* If the subject does not give the appropriate response (*fruits*), the examiner says: *"Yes, and they also both belong to the category Fruits."* No additional instructions or clarifications are given. After the practice trial, the examiner says: *"Now, a hammer and a screwdriver."* Following the response, the examiner administers the second trial by saying: *"Now, matches and a lamp."* A **prompt** (one for the entire abstraction section) may be given if none was used during the example.

**Scoring:** Only the last two pairs are scored. One point is given for each pair correctly answered. The following responses are acceptable:

- hammer- screwdriver = tools, carpentry, construction, work instruments,
- matches- lamp = light, lighting, illumination

The following responses are **not** acceptable:

- hammer- screwdriver = instruments, have handles, metallic objects,
- matches- lamp = fire, hot objects, produce heat

## 10. **Delayed recall:**

**Administration:** The examiner gives the following instructions: *"I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember."* The examiner makes a check mark (✓) for each of the words correctly recalled spontaneously without any cues, in the allocated space.

**Scoring:** **One point is allocated for each word recalled freely without any cues.**

### **Memory index score (MIS):**

**Administration:** Following the delayed free recall trial, the examiner provides a category (semantic) cue for each word the subject was unable to recall. Example: *"I will give you some hints to see if it helps you remember the words, the first word was a body part."* If the subject is unable to recall the word with the category cue, the examiner provides him/her with a multiple choice cue. Example: *"Which of the following words do you think it was, HAND, LEG, or FACE?"* All non-recalled words are prompted in this manner. The examiner identifies the words the subject was able to recall with the help of a cue (category or multiple-choice) by placing a check mark (✓) in the appropriate space. The cues for each word are presented below:



Target Word	Category Cue	Multiple Choice
LEG	body part	hand, leg, face (shoulder, nose)
COTON	type of fabric	silk, cotton, nylon (velvet, denim)
SCHOOL	public building	school, hospital, library (church, store)
TOMATO	type of food	lettuce, tomato, carrot (cucumber, celery)
WHITE	color	purple, white, green (yellow, red)

\* The words in parentheses are to be used if the subject mentions one or two of the multiple choice responses during the category cuing.

**Scoring:** To determine the MIS (which is a sub-score), the examiner attributes points according to the type of recall (see table below). The use of cues provides clinical information on the nature of the memory deficits. For memory deficits due to retrieval failures, performance can be improved with a cue. For memory deficits due to encoding failures, performance does not improve with a cue.

MIS scoring				Total
Number of words recalled spontaneously	...	multiplied by	3	...
Number of words recalled with a category cue	...	multiplied by	2	...
Number of words recalled with a multiple choice cue	...	multiplied by	1	...
Total MIS (add all points)				---/15

## 11. **Orientation:**

**Administration:** The examiner gives the following instructions: “*Tell me today’s date.*” If the subject does not give a complete answer, the examiner prompts accordingly by saying: “*Tell me the [year, month, exact date, and day of the week].*” Then the examiner says: “*Now, tell me the name of this place, and which city it is in.*”

**Scoring:** One point is allocated for each item correctly answered. The date and place (name of hospital, clinic, office) must be exact. No points are allocated if the subject makes an error of one day for the day and date.

**TOTAL SCORE:** Sum all subscores listed on the right-hand side. Add one point for subject who has 12 years or fewer of formal education, for a possible maximum of 30 points. A final total score of 26 and above is considered normal.

Please refer to the MoCA website at [www.mocatest.org](http://www.mocatest.org) for more information on the MoCA.



Issue Number D13, Revised 2016

Editor-in-Chief: Sherry A. Greenberg, PhD, RN, GNP-BC  
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## Use of the Functional Activities Questionnaire in Older Adults with Dementia

By: Ann M. Mayo, DNSc, RN, FAAN  
Hahn School of Nursing & Health Science, University of San Diego

**WHY:** Dementia is a neurodegenerative disease where functional ability in individuals with dementia (IWD) declines over time. The majority of care costs in IWD are directly attributed to functional disability (Hurd, 2013). Compromised functional ability is unsafe for IWD, anxiety provoking for families and costly to health care organizations. Valid and reliable clinical information about functional ability can be used to individualize care and design safe and supportive environments thereby promoting the highest level of independence for individuals with dementia. Therefore, an effective and efficient method for measuring functional ability is important.

**BEST TOOL:** The Functional Activities Questionnaire (FAQ) measures instrumental activities of daily living (IADLs), such as preparing balanced meals and managing personal finances. Since functional changes are noted earlier in the dementia process with IADLs that require a higher cognitive ability compared to basic activities of daily living (ADLs) (Hall, 2011; Peres et al., 2008), this tool is useful to monitor these functional changes over time. The FAQ may be used to differentiate those with mild cognitive impairment and mild Alzheimer's disease. To further exemplify the importance and utilization of the FAQ, thousands of research participants across the United States are administered the FAQ annually as part of the National Alzheimer's Coordinating Center (NACC) longitudinal research study taking place in 29 National Institute on Aging-funded Alzheimer's Disease Centers (Weintraub et al., 2009).

**TARGET POPULATION:** Older adults with normal cognition, mild cognitive impairment, as well as mild, moderate, and advanced dementia (Weintraub et al., 2009). The FAQ is appropriate for clinical settings, such as acute and primary care, rehabilitation, assisted living, and home settings, as well as for research.

**VALIDITY AND RELIABILITY:** In IWD the FAQ is a consistently accurate instrument with good sensitivity (85%) to identify an individual's functional impairment. The FAQ demonstrates high reliability (exceeding 0.90). Tests of validity have been performed on the FAQ establishing it as an instrument for the bedside and research because it can discriminate among different functional levels of individuals, predict neurological exam ratings and mental status scores such as the Folstein Mini-Mental Status Examination (MMSE) and demonstrate sensitivity to change (Assis, 2014; Malek-Ahmadi, 2015; Pfeffer, 1982).

**STRENGTHS AND LIMITATIONS:** The FAQ is efficient to administer to older adults giving consistent results across different professionals and settings including primary care settings, as well as with different forms of dementia (Mayo, 2013; Tabert et al., 2002). As with other instruments that measure functional activities using indirect approaches, there may be over or under estimation of abilities because of the lack of direct observations.

**FOLLOW-UP:** Continued monitoring of IADLs in IWD is important to ensure environmental adaptations keeping these individuals safe. The measurement of IADLs is also important for advancing science. Therefore, the FAQ is an important measure for clinicians and researchers.

### MORE ON THE TOPIC:

Best practice information on care of older adults: <http://consultgeri.org/>.

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## Functional Activities Questionnaire

### Administration

Ask informant to rate patient's ability using the following scoring system:

- Dependent = 3
- Requires assistance = 2
- Has difficulty but does by self = 1
- Normal = 0
- Never did [the activity] but could do now = 0
- Never did and would have difficulty now = 1

1.	Writing checks, paying bills, balancing checkbook	
2.	Assembling tax records, business affairs, or papers	
3.	Shopping alone for clothes, household necessities, or groceries	
4.	Playing a game of skill, working on a hobby	
5.	Heating water, making a cup of coffee, turning off stove after use	
6.	Preparing a balanced meal	
7.	Keeping track of current events	
8.	Paying attention to, understanding, discussing TV, book, magazine	
9.	Remembering appointments, family occasions, holidays, medications	
10.	Traveling out of neighborhood, driving, arranging to take buses	
TOTAL SCORE:		

### Evaluation

Sum scores (range 0-30). Cut-point of 9 (dependent in 3 or more activities) is recommended to indicate impaired function and possible cognitive impairment.

Pfeffer, R.I., Kurosaki, T.T., Harrah, C.H. Jr., Chance, J.M., & Filos, S. (1982). Measurement of functional activities in older adults in the community. *Journal of Gerontology*, 37(3), 323-329. Reprinted with permission of Oxford University Press.



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Issue Number 2, Revised 2019

Editor-in-Chief: Sherry A. Greenberg, PhD, RN, GNP-BC  
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## Katz Index of Independence in Activities of Daily Living (ADL)

By: Donna McCabe, DNP, APRN-BC, GNP  
 New York University Rory Meyers College of Nursing

**WHY:** Age-related changes and health problems frequently show themselves as declines in the functional status of older adults. Decline may place the older adult on a spiral of iatrogenesis leading to further health problems. One of the best ways to evaluate the health status of older adults is through functional assessment, which provides objective data that may indicate future decline or improvement in health status, allowing the nurse to plan and intervene appropriately.

**BEST TOOL:** The Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL, is the most appropriate instrument to assess functional status as a measurement of the client's ability to perform activities of daily living independently. Clinicians typically use the tool to assess function and detect problems in performing activities of daily living and to plan care accordingly. The Index ranks adequacy of performance in the six functions of *bathing, dressing, toileting, transferring, continence, and feeding*. Clients are scored yes/no for independence in each of the six functions. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment.

**TARGET POPULATION:** The instrument is used effectively among older adults in the community and all care settings. The tool is most useful when baseline measurements are taken when the client is well and compared to periodic or subsequent measures.

**VALIDITY AND RELIABILITY:** The Katz tool was originally developed in the late 1950s, it has been modified and simplified and different approaches to scoring have been used. However, it has consistently demonstrated its utility in evaluating functional status in the elderly population. Although no formal reliability and validity reports could be found in the literature, the tool is used extensively as a flag signaling functional capabilities of older adults in clinical and home environments.

**STRENGTHS AND LIMITATIONS:** The Katz ADL Index assesses basic activities of daily living. It does not assess more advanced activities of daily living. Katz developed another scale for instrumental activities of daily living such as heavy housework, shopping, managing finances and telephoning. Although the Katz ADL Index is sensitive to changes in declining health status, it is limited in its ability to measure small increments of change seen in the rehabilitation of older adults. A full comprehensive geriatric assessment should follow when appropriate. The Katz ADL Index is very useful in creating a common language about patient function for all practitioners involved in overall care planning and discharge planning.

### MORE ON THE TOPIC:

Best practice information on care of older adults: <https://consultgeri.org>.

Graf, C. (2006). Functional decline in hospitalized older adults. *AJN*, 106(1), 58-67.

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## Katz Index of Independence in Activities of Daily Living

<b>ACTIVITIES</b> POINTS (1 OR 0)	<b>INDEPENDENCE:</b> (1 POINT) <b>NO</b> supervision, direction or personal assistance	<b>DEPENDENCE:</b> (0 POINTS) <b>WITH</b> supervision, direction, personal assistance or total care
<b>BATHING</b>  POINTS: _____	(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity.	(0 POINTS) Needs help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
<b>DRESSING</b>  POINTS: _____	(1 POINT) Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self or needs to be completely dressed.
<b>TOILETING</b>  POINTS: _____	(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
<b>TRANSFERRING</b>  POINTS: _____	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transferring aides are acceptable.	(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.
<b>CONTINENCE</b>  POINTS: _____	(1 POINT) Exercises complete self control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder.
<b>FEEDING</b>  POINTS: _____	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.

**TOTAL POINTS = \_\_\_\_\_** 6 = *High (patient independent)* 0 = *Low (patient very dependent)*

Slightly adapted from Katz, S., Down, T.D., Cash, H.R., & Grotz, R.C. (1970) Progress in the development of the index of ADL. *The Gerontologist*, 10(1), 20-30.

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The Hartford Institute for Geriatric Nursing recognizes Mary Shelkey, PhD, ARNP and Meredith Wallace Kazer, PhD, APRN, A/GNP-BC as the original authors of this issue.



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Editor-in-Chief: Sherry A. Greenberg, PhD, RN, GNP-BC  
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## The Lawton Instrumental Activities of Daily Living (IADL) Scale

By: Robin Coyne, MSN, RN, AGACNP-BC, Wolters Kluwer

**WHY:** The assessment of functional status is critical when caring for older adults. Normal changes due to aging, acute illness, worsening chronic illness, and hospitalization can contribute to a decline in the ability to perform tasks necessary to live independently in the community. The information from a functional assessment can provide objective data to assist with targeting individualized rehabilitation needs or to plan for specific in home services such as meal preparation, nursing and personal care, home-maker services, financial and medication management, and/or continuous supervision. A functional assessment can also guide the clinician to focus on the person's baseline capabilities, facilitating early recognition of changes that may signify a need either for additional resources or for a medical work-up (Greenberg & McCabe, 2018).

**BEST TOOL:** The Lawton Instrumental Activities of Daily Living Scale (IADL) is an appropriate instrument to assess independent living skills (Lawton & Brody, 1969). These skills are considered more complex than the basic activities of daily living as measured by the Katz Index of ADLs (See *Try This:*® Katz Index of ADLs). The instrument is most useful for identifying how a person is functioning at the present time and for identifying improvement or deterioration over time. There are 8 domains of function measured with the Lawton IADL scale. Historically, women were scored on all 8 areas of function; men were not scored in the domains of food preparation, housekeeping, laundering. However, current recommendations are to assess all domains for both genders (Lawton, Moss, Fulcomer, & Kleban, 2003). Persons are scored according to their highest level of functioning in that category. A summary score ranges from 0 (low function, dependent) to 8 (high function, independent).

**TARGET POPULATION:** This instrument is intended to be used among older adults, and may be used in community, clinic, or hospital settings. The instrument is not useful for institutionalized older adults. It may be used as a baseline assessment tool and to compare baseline function to periodic assessments.

**VALIDITY AND RELIABILITY:** Few studies have been performed to test the Lawton IADL scale psychometric properties. The Lawton IADL Scale was originally tested concurrently with the Physical Self-Maintenance Scale (PSMS). Reliability was established with twelve subjects interviewed by one interviewer with the second rater present but not participating in the interview process. Inter-rater reliability was established at 0.85. The validity of the Lawton IADL was tested by determining the correlation of the Lawton IADL with four scales that measured domains of functional status, the Physical Classification (6-point rating of physical health), Mental Status Questionnaire (10-point test of orientation and memory), Behavior and Adjustment rating scales (4-6-point measure of intellectual, person, behavioral and social adjustment), and the PSMS (6-item ADLs). A total of 180 research subjects participated in the study, however, few received all five evaluations. All correlations were significant at the 0.01 or 0.05 level. To avoid potential gender bias at the time the instrument was developed, specific items were omitted for men. This assessment instrument is widely used both in research and clinical practice.

**STRENGTHS AND LIMITATIONS:** The Lawton IADL is an easy to administer assessment instrument that provides self-reported information about functional skills necessary to live in the community. Administration time is 10-15 minutes. Specific deficits identified can assist nurses and other disciplines in planning for safe hospital discharge.

A limitation of the instrument includes the self-report or surrogate report method of administration rather than a demonstration of the functional task. This may lead either to over-estimation or under-estimation of ability. In addition, the instrument may not be sensitive to small, incremental changes in function.

**FOLLOW-UP:** The identification of new disabilities in these functional domains warrants intervention and further assessment to prevent ongoing decline and to promote safe living conditions for older adults. If using the Lawton IADL tool with an acute hospitalization, nurses should communicate any deficits to the physicians and social workers/case managers for appropriate discharge planning.

### MORE ON THE TOPIC:

Best practice information on care of older adults: <https://consultgeri.org>.

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# 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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The Hartford Institute for Geriatric Nursing recognizes Carla Graf as the original author of this issue.



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## DEMENTIA SEVERITY RATING SCALE©

Total Score: \_\_\_\_\_

NAME: \_\_\_\_\_

DATE: \_\_\_\_\_

PERSON COMPLETING  
FORM: \_\_\_\_\_

Please circle the most appropriate answer.

Do you live with the participant?      No      Yes

How much contact do you have with the participant?

Less than 1 day/week    1 day/week    2 days/week    3-4 days/week  
5 or more days per week

Relationship to participant

Self    Spouse    Sibling    Child    Other Family    Friend    Other \_\_\_\_\_

This form was developed to measure and keep track of symptoms. You will be asked to fill out a form like this with each visit in order to identify changes that occur over time.

In each section, please circle the number that **most closely applies** to the participant.  
This is a general form, so no one description may be exactly right -- please circle the answer that seems to apply most of the time.

**Please circle only one number per section, and be sure to answer all questions.**

### MEMORY

- 0      Normal memory.
- 1      Occasionally forgets things that they were told recently. Does not cause many problems.
- 2      Mild consistent forgetfulness. Remembers recent events but often forgets parts.
- 3      Moderate memory loss. Worse for recent events. May not remember something you just told them. Causes problems with everyday activities.
- 4      Substantial memory loss. Quickly forgets recent or newly-learned things. Can only remember things that they have known for a long time.

- 5 Does not remember basic facts like the day of the week, when last meal was eaten or what the next meal will be.
- 6 Does not remember even the most basic things.

### **SPEECH AND LANGUAGE**

- 0 Normal ability to talk and to understand others.
- 1 Sometimes cannot find a word, but able to carry on conversations.
- 2 Often forgets words. May use the wrong word in its place. Some trouble expressing thoughts and giving answers.
- 3 Usually answers questions using sentences but rarely starts a conversation.
- 4 Answers questions, but responses are often hard to understand or don't make sense. Usually able to follow simple instructions.
- 5 Speech often does not make sense. Can not answer questions or follow instructions.
- 6 Does not respond most of the time.

### **RECOGNITION OF FAMILY MEMBERS**

- 0 Normal - recognizes people and generally knows who they are.
- 1 Usually recognizes grandchildren, cousins or relatives who are **not** seen frequently but may not recall how they are related.
- 2 Usually does not recognize family members who are not seen frequently. Is often confused about how family members such as grandchildren, nieces, or nephews are related to them.
- 3 Sometimes does not recognize close family members or others who they see frequently. May not recognize their children, brothers, or sisters who are not seen on a regular basis.
- 4 Frequently does not recognize spouse or caregiver.
- 5 No recognition or awareness of the presence of others.

### **ORIENTATION TO TIME**

- 0 Normal awareness of time of day and day of week.
- 1 Some confusion about what time it is or what day of the week, but not severe enough to interfere with everyday activities.
- 2 Frequently confused about time of day.
- 3 Almost always confused about the time of day.
- 4 Seems completely unaware of time.

### **ORIENTATION TO PLACE**

- 0 Normal awareness of where they are even in new places.
- 1 Sometimes disoriented in new places.
- 2 Frequently disoriented in new places.
- 3 Usually disoriented, even in familiar places. May forget that they are already at home.
- 4 Almost always confused about place.

### **ABILITY TO MAKE DECISIONS**

- 0 Normal - as able to make decisions as before.
- 1 Only some difficulty making decisions that arise in day-to-day life.
- 2 Moderate difficulty. Gets confused when things get complicated or plans change.
- 3 Rarely makes any important decisions. Gets confused easily.
- 4 Not able to understand what is happening most of the time.

### **SOCIAL AND COMMUNITY ACTIVITY**

- 0 Normal - acts the same with people as before
- 1 Only mild problems that are not really important, but clearly acts differently from previous years.
- 2 Can still take part in community activities without help. May appear normal to people who don't know them.
- 3 Often has trouble dealing with people outside the home without help from caregiver. Usually can participate in quiet home activities with friends. The problem is clear to anyone who sees them.
- 4 No longer takes part in any real way in activities at home involving other people. Can only deal with the primary caregiver.
- 5 Little or no response even to primary caregiver.

### **HOME ACTIVITIES AND RESPONSIBILITIES**

- 0 Normal. No decline in ability to do things around the house.
- 1 Some problems with home activities. May have more trouble with money management (paying bills) and fixing things. Can still go to a store, cook or clean. Still watches TV or reads a newspaper with interest and understanding.
- 2 Makes mistakes with easy tasks like going to a store, cooking or cleaning. Losing interest in the newspaper, TV or radio. Often can't follow a long conversation on a single topic.
- 3 Not able to shop, cook or clean without a lot of help. Does not understand the newspaper or the TV. Cannot follow a conversation.
- 4 No longer does any home-based activities.

### **PERSONAL CARE - CLEANLINESS**

- 0 Normal. Takes care of self as well as they used to.
- 1 Sometimes forgets to wash, shave, comb hair, or may dress in wrong type of clothes. Not as neat as they used to be.
- 2 Requires help with dressing, washing and personal grooming.
- 3 Totally dependent on help for personal care.

### **EATING**

- 0 Normal, does not need help in eating food that is served to them.
- 1 May need help cutting food or have trouble with some foods, but basically able to eat by themselves.
- 2 Generally able to feed themselves but may require some help. May lose interest during the meal.
- 3 Needs to be fed. May have trouble swallowing.

### **CONTROL OF URINATION AND BOWELS**

- 0 Normal - does not have problems controlling urination or bowels except for physical problems.
- 1 Rarely fails to control urination (generally less than one accident per month).
- 2 Occasional failure to control urination (about once a week or less).
- 3 Frequently fails to control urination (more than once a week).
- 4 Generally fails to control urination and frequently can not control bowels.

### **ABILITY TO GET FROM PLACE TO PLACE**

- 0 Normal, able to get around on their own. (May have physical problems that require a cane or walker).
- 1 Sometimes gets confused when driving or taking public transportation, especially in new places. Able to walk places alone.
- 2 Cannot drive or take public transportation alone, even in familiar places. Can walk alone outside for short distances. Might get lost if walking too far from home.
- 3 Cannot be left outside alone. Can get around the house without getting lost or confused.
- 4 Gets confused and needs help finding their way around the house.
- 5 Almost always in a bed or chair. May be able to walk a few steps with help, but lacks sense of direction.
- 6 Always in bed. Unable to sit or stand.

# npiTEST

## **The Neuropsychiatric Inventory Questionnaire: Background and Administration**

By Jeffrey L. Cummings, MD



## The Neuropsychiatric Inventory–Questionnaire: Background and Administration

The Neuropsychiatric Inventory–Questionnaire (NPI-Q) was developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in routine clinical practice settings (Kaufer et al, J Neuropsychiatry Clin Neurosci 2000, 12:233-239). The NPI-Q is adapted from the NPI (Cummings et al, Neurology 1994; 44:2308-2314), a validated informant-based interview that assesses neuropsychiatric symptoms over the previous month. The original NPI included 10 neuropsychiatric domains; two others, Nighttime Behavioral Disturbances and Appetite/Eating Changes, have subsequently been added. Another recent modification of the original NPI is the addition of a Caregiver Distress Scale for evaluating the psychological impact of neuropsychiatric symptoms reported to be present (Kaufer et al, JAGS, 1998;46:210-215). The NPI-Q includes both of these additions.

The NPI-Q is designed to be a self-administered questionnaire completed by informants about patients for whom they care. Each of the 12 NPI-Q domains contains a survey question that reflects cardinal symptoms of that domain. Initial responses to each domain question are "Yes" (present) or "No" (absent). If the response to the domain question is "No", the informant goes to the next question. If "Yes", the informant then rates both the Severity of the symptoms present within the last month on a 3-point scale and the associated impact of the symptom manifestations on them (i.e. Caregiver Distress) using a 5-point scale. The NPI-Q provides symptom Severity and Distress ratings for each symptom reported, and total Severity and Distress scores reflecting the sum of individual domain scores.

Most informants will be able to complete the NPI-Q in 5 minutes or less. It is recommended that responses to the NPI-Q be reviewed for completeness by a clinician and for clarifying uncertainties after each administration. The first time an informant completes the NPI-Q, it may be useful to verbally review the instructions. In some instances, it may be necessary to conduct the NPI-Q in part or entirely as an interview.

The NPI and NPI-Q are both copyright-protected by Jeffrey L. Cummings, MD. The NPI-Q was developed by Daniel Kaufer, MD with permission. **Use of the NPI or NPI-Q in investigational studies sponsored in whole or part by for-profit entities is prohibited without express written consent.**

For inquiries regarding the NPI-Q, contact:

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Los Angeles, CA 90095  
jcummings@mednet.ucla.edu

The NPI-Q can be found at:  
[www.NPItest.net](http://www.NPItest.net)

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(s) has been present in the last month. Otherwise, circle "No". For each item marked "Yes":

a) 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)

b) Rate the **DISTRESS** you experience due to 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 carefully. Ask for assistance if you have any questions.

<b>Delusions</b>	Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?
------------------	--

Yes	No	SEVERITY: 1 2 3	DISTRESS: 0 1 2 3 4 5
-----	----	-----------------	-----------------------

<b>Hallucinations</b>	Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?
-----------------------	---

Yes	No	SEVERITY: 1 2 3	DISTRESS: 0 1 2 3 4 5
-----	----	-----------------	-----------------------

<b>Agitation/Aggression</b>	Is the patient resistive to help from others at times, or hard to handle?
-----------------------------	---

Yes	No	SEVERITY: 1 2 3	DISTRESS: 0 1 2 3 4 5
-----	----	-----------------	-----------------------

**Depression/Dysphoria** Does the patient seem sad or say that he /she is depressed?

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/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/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/Indifference** Does the patient seem less interested in his/her usual activities or 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, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?

Yes    No                      SEVERITY: 1   2   3                      DISTRESS: 0   1   2   3   4   5

**Irritability/Lability** Is the patient impatient and cranky? Does he/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/Eating** Has the patient lost or gained weight, or had a change in the  
type of food he/she likes?

**Yes      No                      SEVERITY: 1   2   3                      DISTRESS: 0   1   2   3   4   5**

## NPI-Q SUMMARY

	No	Severity			Caregiver Distress					
<b>Delusions</b>	0	1	2	3	0	1	2	3	4	5
<b>Hallucinations</b>	0	1	2	3	0	1	2	3	4	5
<b>Agitation/Aggression</b>	0	1	2	3	0	1	2	3	4	5
<b>Dysphoria/Depression</b>	0	1	2	3	0	1	2	3	4	5
<b>Anxiety</b>	0	1	2	3	0	1	2	3	4	5
<b>Euphoria/Elation</b>	0	1	2	3	0	1	2	3	4	5
<b>Apathy/Indifference</b>	0	1	2	3	0	1	2	3	4	5
<b>Disinhibition</b>	0	1	2	3	0	1	2	3	4	5
<b>Irritability/Lability</b>	0	1	2	3	0	1	2	3	4	5
<b>Aberrant Motor</b>	0	1	2	3	0	1	2	3	4	5
<b>Nighttime Behavior</b>	0	1	2	3	0	1	2	3	4	5
<b>Appetite/Eating</b>	0	1	2	3	0	1	2	3	4	5
<b>TOTAL</b>										

**BEHAV5**

Borson, Sadak ©

Please check yes for the behaviors that **you have observed** in your **care recipient** in the **past month**.

<b>1. AGITATION/AGGRESSION</b>  Does your care recipient get angry or hostile? Resist care from others?	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>2. HALLUCINATIONS</b>  Does your care recipient see and/or hear things that no one else can see or hear?	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>3. IRRITABILITY/ FREQUENTLY CHANGING MOOD</b>  Does your care recipient act impatient and cranky? Does his or her mood frequently change for no apparent reason?	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>4. SUSPICIOUSNESS/PARANOIA</b>  Does your care recipient act suspicious without good reason (example: believes that others are stealing from him or her, or planning to harm him or her in some way)?	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>5. INDIFFERENCE/SOCIAL WITHDRAWAL</b>  Does your care recipient seem less interested in his or her usual activities and in the activities and plans of others?	<input type="checkbox"/> Yes <input type="checkbox"/> No

BEHAV5

V1.0 9.2.16

Page 1 of 1

Participant ID: \_\_\_\_\_

Date: \_\_\_\_\_

Used with permission from Soo Borson.

Over the last two weeks, how often have you been bothered by any of the following problems? <i>(Use “✓” to indicate your answer)</i>	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3

FOR OFFICE CODING 0 + \_\_\_\_\_ + \_\_\_\_\_ + \_\_\_\_\_

=Total Score: \_\_\_\_\_

List all current medications.

Medications	Dosage	Review date

Name the caregiver who assists with or oversees medication management:



**Safety Assessment Checklist**

If the patient or caregiver answers yes to questions 1 and 3-7 or no to question 2, refer to the Safety Assessment Guide for further evaluation. When working with patients living with dementia, it is recommended that you also consult with a family member, friend or caregiver, as the patient's judgment, memory and decreased cognitive skills may impact insight into the illness and the ability to provide accurate reporting.

Questions	Yes	No
1. Is the patient still driving?		
2. Is the patient taking medications as prescribed?		
3. Are there concerns about safety in the home?		
4. Has the patient gotten lost in familiar places or wandered?		
5. Are firearms present in the home?		
6. Has the patient experienced unsteadiness or sustained falls?		
7. Does the patient live alone?		

## Driving

A patient's functional ability — not age or diagnosis — should dictate when it's time to retire from driving. Look for changes from his or her baseline.

Questions to ask patient	Questions to ask family/caregiver	Considerations	Resources
<p>Are you still driving?</p> <p>How have your driving skills or behaviors changed?</p> <p>Have you had any traffic accidents?</p> <p>Have you considered making a plan for when you are no longer able to drive?</p>	<p>Is the patient still driving?</p> <p>Is the patient a good driver?</p> <p>Has the patient been involved in any recent accidents, including fender benders, or been issued any tickets?</p> <p>Do you have any concerns about a passenger riding with the patient?</p>	<p>These questions should be asked during every visit for as long as the patient is still driving.</p> <p>Driving requires the ability to multitask. High-risk driving is increasingly linked to higher order ADL impairment.</p> <p>Both the person with dementia and the family need to be aware that functional abilities will change over time, making driving no longer possible. Plans should be made for when that time comes.</p> <p>Driving represents independence and the loss of the ability to drive can be very difficult to accept. Acknowledging this loss of independence with the patient can be helpful, along with discussing other available transportation options.</p> <p>There may come a time when the person doesn't understand why he or she can no longer drive safely. Once other measures to prevent the person from driving have been exhausted, counsel the family or caregiver about removing the person's access to the car, disabling the vehicle or taking away the keys. Sometimes it can be helpful to write out a "retire from driving" prescription.</p>	<p><a href="#">Alzheimer's Association Dementia and Driving Resource Center</a></p> <p><a href="#">American Occupational Therapy Association</a></p> <p><a href="#">Driving Safety Guides</a></p> <p><a href="#">Aging Life Care Association</a></p>

<https://alz.org/help-support/caregiving/safety/dementia-driving>

[https://myaota.aota.org/driver\\_search/](https://myaota.aota.org/driver_search/)

<https://www.thehartford.com/resources/mature-market-excellence/publications-on-aging>

[https://www.aginglifecare.org//ALCA/About\\_Aging\\_Life\\_Care/Find\\_an\\_Aging\\_Life\\_Care\\_Expert/ALCA/About\\_Aging\\_Life\\_Care/Search/Find\\_an\\_Expert.aspx?hkey=78a6cb03-e912-4993-9b68-df1573e9d8af%20](https://www.aginglifecare.org//ALCA/About_Aging_Life_Care/Find_an_Aging_Life_Care_Expert/ALCA/About_Aging_Life_Care/Search/Find_an_Expert.aspx?hkey=78a6cb03-e912-4993-9b68-df1573e9d8af%20)

## Managing Medications

Managing medications is a common difficulty for patients with cognitive impairment and/or those taking multiple medications, thus requiring assistance, even when the person is in the early stage.

Questions to ask patient	Questions to ask family/caregiver	Considerations	Resources
<p>It's not uncommon for older adults to sometimes forget to take their medications. Does that ever happen to you?</p> <p>What do you do to help remember to take your medications?</p> <p>How do you tell your medications apart? Do you use pill boxes?</p> <p>Who fills your pill boxes? How do you refill your prescriptions?</p>	<p>How is the patient doing with his or her medications?</p> <p>How confident are you that he or she is taking them as directed?</p> <p>Do you ever notice that there are too many or not enough pills at the end of the month?</p>	<p>We cannot rely on self-management of conditions for patients with dementia.</p> <p>Tools like pill boxes, a reminder call from a family member or special bottles with caps that count how many times the bottle has been opened may be helpful in managing medications.</p> <p>Family members or caregivers can provide assistance by asking the pharmacist to distribute medication in a pill box and by setting alarms on a phone or watch as medication reminders.</p>	<p><a href="#">Medication Management: A Family Caregiver's Guide</a></p> <p><a href="#">Medication Safety</a></p> <p><a href="#">Medi-Cog</a></p>

[https://www.nextstepincare.org/Caregiver\\_Home/Medication\\_Management\\_Guide/](https://www.nextstepincare.org/Caregiver_Home/Medication_Management_Guide/)

<https://www.alz.org/media/Documents/alzheimers-dementia-medication-safety-ts.pdf>

<https://www.pharmacy.umaryland.edu/media/SOP/medmanagementumarylandedu/MediCogBlank.pdf>

## Home Safety

It is important to educate the family/caregiver about safety in the home early in the process so they can make appropriate modifications to the home and learn how to continually assess safety as the disease progresses.

Questions to ask patient	Questions to ask family/caregiver	Considerations	Resources
<p>Have you had any safety-related incidents at home?</p> <p>Do you feel safe in your home?</p> <p>Do you use the stove to cook?</p> <p>Is it becoming more difficult for you to complete chores?</p> <p>Do you ever smoke while alone in your home?</p>	<p>Do you feel comfortable leaving the person home alone?</p> <p>Have you noticed any burned pans or other signs of issues with the stove or other appliances?</p> <p>Do you have any concerns about the person's cooking or eating habits?</p> <p>Are there working smoke detectors and fire extinguishers in the home?</p> <p>Are there any concerns about the patient harming themselves or others?</p>	<p>There will come a time when the person should not be left alone. However, he or she may still be able to participate in some chores with supervision.</p> <p>Keep an eye on the person's ability to conduct typical household tasks, such as cooking and using appliances and tools. Adjust as necessary.</p> <p>A speech and/or occupational therapist specializing in dementia can provide additional customized strategies to support the person with dementia and the family/caregiver.</p>	<p><a href="#">Alzheimer's Association Safety Resources</a></p> <p><a href="#">Simple Solutions: Practical Ideas and Products to Enhance Independent Living</a></p> <p><a href="#">Alzheimer's Association Home Safety Checklist</a></p>

<https://alz.org/help-support/caregiving/safety>

[https://s0.hfdstatic.com/sites/the\\_hartford/files/simple-solutions-2012.pdf](https://s0.hfdstatic.com/sites/the_hartford/files/simple-solutions-2012.pdf)

<https://alz.org/media/Documents/alzheimers-dementia-home-safety-checklist.pdf?>

## Wandering and getting lost

Getting lost can occur at any stage of the disease; however, wandering behavior often occurs during the middle stage. It's important to educate the person with dementia and their family/caregiver about the possibility of wandering and getting lost, and how to be prepared.

Questions to ask patient	Questions to ask family/caregiver	Considerations	Resources
Have you ever gotten lost in places that are familiar to you?	<p>Has the patient ever come home much later than expected without an explanation?</p> <p>Does the patient ever try to leave the house or ask to "go home" when he or she is already at home?</p> <p>Has the patient ever gotten lost going to or coming from a familiar place?</p>	<p>For the person who is still independently active in the community:</p> <ul style="list-style-type: none"> <li>• Make sure the person has an In Case of Emergency (ICE) contact in his or her phone.</li> <li>• Consider enrolling in a wandering response service. Contact the Alzheimer's Association 24/7 Helpline (800.272.3900) for more information.</li> <li>• Consider using technology such as GPS devices or mobile apps that offer location tracking services.</li> </ul> <p>For the person who is at risk for wandering:</p> <ul style="list-style-type: none"> <li>• Set up structured and engaging activities throughout the day to help discourage wandering behavior. Include exercise, if possible.</li> <li>• Disguise the exits with wall hangings.</li> <li>• Put an alarm on the door so you are aware when it is opened.</li> </ul>	<a href="#">Tips on wandering/getting lost</a>

## Firearms

There may come a time when the patient may not recognize family members or friends. It is not uncommon for a person with dementia to believe that a stranger has entered his or her home when it is, in fact, a relative or caregiver. If firearms are accessible, this can become a dangerous situation.

Questions to ask patient	Questions to ask family/caregiver	Considerations	Resources
Do you have firearms in your home?	Are there firearms in the home?	<p>If possible, remove all firearms from the home. If that isn't an option, keep ammunition stored separately from the weapon and ensure that both are kept in a locked cabinet or gun safe.</p> <p>If the patient is reluctant to remove the firearms, encourage him or her to consider "gifting" the firearms to another family member or friend.</p> <p>If necessary, ask local law enforcement for assistance in removing the firearms from the home. The family may receive compensation from a gun buyback program.</p>	<a href="https://www.alz.org/media/Documents/alzheimers-dementia-staying-safe-ts.pdf">Alzheimer's Association Staying Safe Topic Sheet</a>

<https://www.alz.org/media/Documents/alzheimers-dementia-staying-safe-ts.pdf>

## Falling

Patients with dementia can be at risk for falls due to the changes they experience in vision and mobility.

Questions to ask patient	Questions to ask family/caregiver	Considerations	Resources
Do you ever feel unsteady on your feet?	Does the patient seem unsteady on his or her feet?	Order an evaluation with a physical therapist to assess for fall risk.	<a href="https://www.cdc.gov/steady/materials.html">Steady Materials for Health Care Providers</a>
Have you fallen recently?	Has the patient fallen recently?	Refer the caregiver to education about proper transfer techniques.	
Are you limiting outings or travel due to fear of falling?	Has the patient limited outings or travel due to fear of falling?	Remove throw rugs in the home.	

<https://www.cdc.gov/steady/materials.html>

## Living Alone

Individuals with dementia who live alone present unique challenges. Because of the disease, they may not accurately report information. It can be helpful to have a conversation with the person to help you assess whether their level of cognitive decline is impacting their ability to live alone. Keep in mind that many people who live alone also already have a family member, friend or neighbor who provides assistance in the home.

Questions to ask patient	Questions to ask family/caregiver	Considerations	Resources
<p>Do you live alone?</p> <p>Tell me about a good day. What works well for you in your routine and what are your challenges?</p> <p>It is not uncommon for older adults to need some assistance to remember to take their medications. How do you manage that?</p> <p>Do you ever feel lonely, isolated or scared?</p> <p>Are you having any challenges getting to appointments, visiting friends or running errands?</p> <p>Have you noticed any changes in your eating habits?</p> <p>Do you have any support services that come into the home?</p> <p>Have you had any trouble paying your bills or balancing your checkbook?</p> <p><i>If the patient came to the appointment alone:</i> There is a lot for us to go over during these appointments. It may be helpful to bring a friend or family member with you to help you keep track of everything we discuss. Is there someone who can join you for your next appointment?</p>	<p>Have you thought about when it will no longer be safe for the patient to live alone?</p> <p>Do you have any concerns about the patient's ability to live alone?</p> <p>Are you confident that the patient is:</p> <ul style="list-style-type: none"> <li>• Eating regularly?</li> <li>• Getting to appointments?</li> <li>• Managing finances?</li> <li>• Able to shop, clean and prepare meals?</li> </ul> <p>Do you have any support services that come into the home?</p>	<p>Patients who exhibit any of the following behaviors can no longer safely live alone. Plans should be made for more appropriate housing:</p> <ul style="list-style-type: none"> <li>• Delusional or paranoid behavior or thinking.</li> <li>• Serious fall risk (or has fallen).</li> <li>• Unable to remember to take medications, posing a dangerous risk to his or her health.</li> <li>• Forgetting to eat and/or drink regularly.</li> <li>• Unable to use a stove or other tools and appliances without posing a dangerous risk to his or her health.</li> </ul> <p>A diagnosis of dementia and the resulting changes in function and/or social withdrawal may cause a person to feel increased loneliness or isolation. This may in turn impact mood, function and self-care.</p> <p>Changes in thinking may reduce the patient's ability to make appropriate decisions about self-care as the disease progresses. Difficulty managing personal hygiene can lead to unsafe living conditions.</p>	<p><a href="#">Alzheimer's Association If You Live Alone</a></p> <p><small>This is an official publication of the Alzheimer's Association but may be distributed freely and without charge by unaffiliated organizations and individuals. Such distribution does not constitute an endorsement of these parties or their activities by the Alzheimer's Association.</small></p> <p><small>© 2023 Alzheimer's Association®. All rights reserved.</small></p>

## Questions to ask the individuals who will provide care and assistance to the patient with dementia:

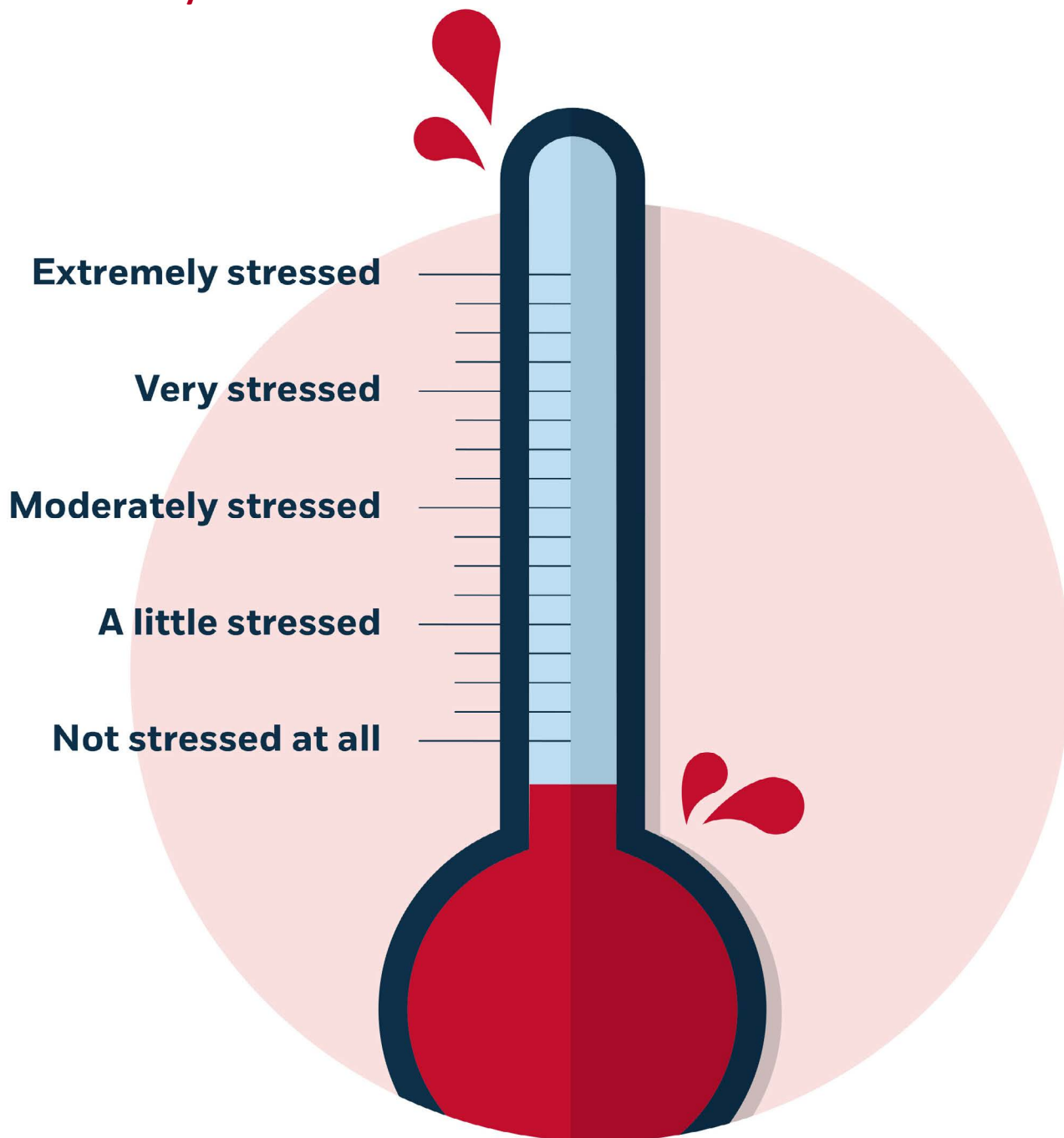
Questions	Yes	No	Resources
Do you understand Alzheimer's and other dementias?			<p><b>Alzheimer's Association®</b>  <a href="http://alz.org">alz.org</a>  <b>800.272.3900</b>            Provides disease education, support groups, and personalized care consultation in person, online and through a free 24/7 Helpline.</p> <p><b>Alzheimer's Disease Education and Referral (ADEAR)</b>  <a href="http://nia.nih.gov/alzheimers">nia.nih.gov/alzheimers</a>            Offers disease information online or by phone for individuals with Alzheimer's or other dementias and their families.</p> <p><b>Administration on Community Living</b>  <a href="http://alzheimers.gov">alzheimers.gov</a>            Supports individuals living with Alzheimer's or other dementias and their caregivers by increasing access to community resources.</p>
Do you know where you can obtain additional information about the disease?			
Are you able and willing to provide care and/or assistance?			<p><b>Alzheimer's Association</b>  <a href="http://alz.org">alz.org</a>  <b>800.272.3900</b>            Care consultants are available to talk all day, every day via the 24/7 Helpline, and support groups take place online and in communities nationwide.</p> <p><b>ALZConnected®</b>  <a href="http://alzconnected.org">alzconnected.org</a>            Online community that connects individuals facing the disease and provides online support.</p> <p><b>Alzheimer's Association &amp; AARP Community Resource Finder</b>  <a href="http://alz.org/CRF">alz.org/CRF</a>            Find local programs, resources and support services.</p>
Do you know where you can receive support as a caregiver?			<p><b>Aging Life Care Association</b>  <a href="http://aginglifecare.org">aginglifecare.org</a>            Locate a geriatric care manager.</p> <p><b>Family Caregiver Alliance</b>  <a href="http://caregiver.org">caregiver.org</a>            Offers support for family and friends providing long-term, in-home care.</p> <p><b>Eldercare Locator</b>  <a href="http://eldercare.acl.gov">eldercare.acl.gov</a>            Connects older adults and their caregivers with local services and provides resource referrals and contact information for state and local agencies on aging.</p>



## My Stress Thermometer

*STRESS: Feeling tense, nervous, anxious, restless, or unable to sleep because your mind is troubled all the time.\**

**Please mark your current stress level on the thermometer:**



Questions	Yes	No	Resources
Have wishes or desires for end-of-life care been discussed?			<p><b>Aging with Dignity — Five Wishes</b>  <a href="https://agingwithdignity.org">agingwithdignity.org</a>  Provides resources for end-of-life planning.</p> <p><b>The Conversation Project</b>  <a href="https://theconversationproject.org">theconversationproject.org</a>  Offers a guide for how to talk about the end of life.</p>
Is a power of attorney in place for financial needs?			<p><b>Alzheimer’s Association</b>  <a href="https://alz.org/care/alzheimers-dementia-common-costs.asp">alz.org/care/alzheimers-dementia-common-costs.asp</a>  Provides information on costs to expect and tips for financial planning.</p>
Is a power of attorney in place for health care decisions?			<p><b>National Association for Elder Law Attorneys</b>  <a href="https://naela.org">naela.org</a>  Offers a directory of elder law attorneys.</p>
Is palliative or hospice care appropriate for the patient?			<p><b>National Hospice and Palliative Care Organization</b>  <a href="https://www.nhpco.org/find-a-care-provider/">https://www.nhpco.org/find-a-care-provider/</a>  Provides information about hospice and palliative care and local hospice and palliative care organizations.</p>

## Caregiving

### Administration on Community Living

[alzheimers.gov](https://www.alzheimers.gov)

Supports individuals living with Alzheimer's disease or other dementias and their caregivers by increasing access to community resources.

### Aging Life Care Association

[aginglifecare.org](https://aginglifecare.org)

Locate a geriatric care manager.

### ALZConnected®

[alzconnected.org](https://alzconnected.org)

Online community that connects individuals facing the disease and provides online support.

### Alzheimer's Association®

[alz.org](https://www.alz.org)

800.272.3900

Provides disease education, support groups, and personalized care consultation in person, online and through a free 24/7 Helpline.

### Alzheimer's Disease Education and Referral (ADEAR)

[nia.nih.gov/alzheimers](https://nia.nih.gov/alzheimers)

800.438.4380

Offers disease information online or by phone for individuals with Alzheimer's or other dementias and their families.

### Alzheimer's Association & AARP Community Resource Finder

[alz.org/CRF](https://www.alz.org/CRF)

Find local programs, resources and support services.

### Family Caregiver Alliance

[caregiver.org](https://www.caregiver.org)

Offers support for family and friends providing long-term, in-home care.

### Eldercare Locator

[eldercare.acl.gov](https://eldercare.acl.gov)

Connects older adults and their caregivers with local services and provides resource referrals and contact information for state and local agencies on aging.

## Safety

### Aging Life Care Association

[https://www.aginglifecare.org/ALCA/About\\_Aging\\_Life\\_Care/Find\\_an\\_Aging\\_Life\\_Care\\_Expert/ALCA/About\\_Aging\\_Life\\_Care/Search/Find\\_an\\_Expert.aspx?hkey=78a6cb03-e912-4993-9b68-df1573e9d8af](https://www.aginglifecare.org/ALCA/About_Aging_Life_Care/Find_an_Aging_Life_Care_Expert/ALCA/About_Aging_Life_Care/Search/Find_an_Expert.aspx?hkey=78a6cb03-e912-4993-9b68-df1573e9d8af)

### Alzheimer's Association Dementia and Driving Resource Center

[alz.org/driving](https://www.alz.org/driving)

### Alzheimer's Association Safety Center

[alz.org/safety](https://www.alz.org/safety)

### American Occupational Therapy Association

[myaota.aota.org/driver\\_search](https://myaota.aota.org/driver_search)

### Car Safety Guides

[thehartford.com/resources/mature-market-excellence/publications-on-aging](https://thehartford.com/resources/mature-market-excellence/publications-on-aging)

### If You Live Alone

[alz.org/i-have-alz/if-you-live-alone.asp](https://www.alz.org/i-have-alz/if-you-live-alone.asp)

### Medication Management: A Family Caregiver's Guide

[https://www.nextstepincare.org/Caregiver\\_Home/Medication\\_Management\\_Guide/](https://www.nextstepincare.org/Caregiver_Home/Medication_Management_Guide/)

### Medication Safety

[alz.org/care/dementia-medication-drug-safety.asp](https://www.alz.org/care/dementia-medication-drug-safety.asp)

### Medi-Cog

[pharmacy.umaryland.edu/practice/medmanagement/assisted\\_living/Tools-to-Assess-Self-Administration-of-Medication/](https://pharmacy.umaryland.edu/practice/medmanagement/assisted_living/Tools-to-Assess-Self-Administration-of-Medication/)

### Simple Solutions: Practical Ideas and Products to Enhance Independent Living

[thehartford.com/resources/mature-market-excellence/publications-on-aging](https://thehartford.com/resources/mature-market-excellence/publications-on-aging)

### Staying Safe brochure

[alz.org/media/documents/alzheimers-dementia-staying-safe-with-alzheimers-b.pdf](https://www.alz.org/media/documents/alzheimers-dementia-staying-safe-with-alzheimers-b.pdf)

### Steady Materials for Health Care Providers

[cdc.gov/steady/materials.html](https://www.cdc.gov/steady/materials.html)

### Wandering and Getting Lost

[alz.org/care/alzheimers-dementia-wandering.asp](https://www.alz.org/care/alzheimers-dementia-wandering.asp)

## End-of-Life

### Aging with Dignity — Five Wishes

[agingwithdignity.org](https://www.agingwithdignity.org)

Resources for end-of-life planning.

### Alzheimer's Association

[alz.org/help-support/caregiving/financial-legal-planning/planning-for-care-costs](https://www.alz.org/help-support/caregiving/financial-legal-planning/planning-for-care-costs)

Provides information on costs to expect and tips for financial planning.

### The Conversation Project

[theconversationproject.org](https://theconversationproject.org)

Offers a guide for how to talk about the end of life.

### National Association for Elder Law Attorneys

[naela.org](https://www.naela.org)

Offers a directory of elder law attorneys.

### National Hospice and Palliative Care Organization

Update with this link: <https://www.nhpco.org/find-a-care-provider/>

Provides information about hospice and palliative care and local hospice and palliative care organizations.