

npiTEST

Neuropsychiatric Inventory (NPI)

Comprehensive Assessment of Psychopathology in
Patients with Dementia

By Jeffrey L. Cummings, MD

Neuropsychiatric Inventory (NPI):

Instructions for Use and Administration

I. Purpose of the NPI

The purpose of the Neuropsychiatric Inventory (NPI) is to obtain information on the presence of psychopathology in patients with brain disorders. The NPI was developed for application to patients with Alzheimer's disease and other dementias, but it may be useful in the assessment of behavioral changes in other conditions. Ten behavioral and two neurovegetative areas are included in the NPI:

Delusions
Hallucinations
Agitation/Aggression
Depression
Anxiety
Elation/Euphoria
Apathy/Indifference
Disinhibition
Irritability
Aberrant motor behavior

Sleep and Nighttime Behavior Disorders
Appetite and Eating Disorders

II. Administration of the NPI

A. NPI Interview

The NPI is based on responses from an informed caregiver, preferably one living with the patient. If an informed observer is not available, this instrument cannot be used or must be modified. The interview is best conducted with the caregiver in the absence of the patient to facilitate an open discussion of behaviors that may be difficult to describe with the patient present. Several points should be made when you introduce the NPI interview to the caregiver:

- Purpose of the interview
- Ratings - frequency, severity, distress (described below)
- Answers apply to behaviors that are new since the onset of the disease and have been present for the past four weeks or other defined period
- Questions can usually be answered with “yes” or “no” and responses should be brief

When beginning the inventory, say to the caregiver “These questions are designed to evaluate your [husband's/wife's/etc] behavior. They can usually be answered ‘yes’ or ‘no’ so please try to be brief in your responses.” If the caregiver lapses into elaborate responses that provide little useful information, he/she may be reminded of the need to be brief. Some of the issues raised with this are

very emotionally disturbing to caregivers and the interviewer should reassure the caregiver that they will discuss the problems in more detail after completion of the inventory.

Questions should be asked exactly as written. Clarification should be provided if the caregiver does not understand the question. Acceptable clarifications are restatements of the questions in alternate terms.

B. Changes in Behavior

The questions pertain to changes in the patient's behavior that have appeared since the onset of the illness. Behaviors that have been present throughout the patient's life and have not changed in the course of the illness are not scored even if they are abnormal (e.g., anxiety, depression). Behaviors that have been present throughout life but have changed since the illness are scored (e.g., the patient has always been apathetic but there has been a notable increase in apathy during the period of inquiry).

The NPI is typically used to assess changes in the patient's behavior that have appeared in a defined period of time (e.g., in the past four weeks or other defined interval). In some studies, the NPI may be used to address changes occurring in response to treatment or that have changed since the last clinic visit. The time frame of the question would then be revised to reflect this interest in recent changes. For example, the questions might be phrased "Since he/she began treatment with the new medications..." or "Since the dosage of _____ was increased"

C. Screening Questions

The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, mark NO and proceed to the next screening question without asking the subquestions. If the answer to the screening question is positive or if there are any uncertainties in the caregiver's response or any inconsistencies between the response and other information known by the clinician (e.g., the caregiver responds negatively to the euphoria screening question but the patient appears euphoric to the clinician), the category is marked YES and is explored in more depth with the subquestions. If the subquestions confirm the screening question, the severity and frequency of the behavior are determined according to the criteria provided with each behavior.

In some cases, the caregiver will provide a positive response to the screening question and a negative reply to all subquestions. If this happens, ask the caregiver to expand on why he/she responded affirmatively to the screen. If he/she provides information relevant to the behavioral domain but in different terms, the behavior should be scored for severity and frequency as usual. If the original affirmative response was erroneous, leading to a failure to endorse any subquestions, then the behavior is changed to "NO" on the screen.

Some sections such as the questions pertaining to appetite are framed so as to capture whether there is an increase or decrease in the behavior (increased or decreased appetite or weight). If the caregiver answers "yes" to the first member of the paired questions (such as has the patient's weight decreased?), do not ask the second question (has the patient's weight increased?) since the answer to the second question is contained in the answer to the first. If the caregiver answers "no" to the first member of the pair of questions, then the second question must be asked.

D. Frequency and Severity Ratings

When determining frequency and severity, use the behaviors identified by the subquestions as most aberrant. For example, if the caregiver indicates that resistive behavior is particularly problematic when you are asking the subquestions of the agitation section, then use resistive behavior to prompt judgments regarding the frequency and severity of agitation. If two behaviors are very problematic, use the frequency and severity of both behaviors to score the item. For example, if the patient has two or more types of delusions, then use the severity and the frequency of all delusional behaviors to phrase the questions regarding severity and frequency.

When determining frequency, say to the person being interviewed "Now I want to find out how often these things [define using the description of the behaviors noted as most problematic on the subquestions] occur. Would you say that they occur less than once per week, about once per week, several times per week but not every day, or every day?" Some behaviors such as apathy eventually become continuously present, and then "are constantly present" can be substituted for "every day."

When determining severity, tell the person being interviewed "Now I would like to find out how severe these behaviors are. By severity, I mean how disturbing or disabling they are for the patient. Would you say that [the behaviors] are mild, moderate, or severe?" Additional descriptors are provided in each section that may be used to help the interviewer clarify each grade of severity. In each case, be sure that the caregiver provides you with a definite answer as to the frequency and severity of the behaviors. Do not guess what you think the caregiver would say based on your discussion.

We have found it helpful to provide the caregiver with a piece of paper on which is written the frequency and severity descriptions (less than once per week, about once per week, several times per week and daily or continuously for frequency; and mild, moderate, and severe for severity) to allow him/her to visualize the response alternatives. This also saves the examiner from reiterating the alternatives with each question.

E. Not Applicable Designations

In very impaired patients or in patients with special medical circumstances, a set of questions may not be applicable. For example, bed-bound patients may exhibit hallucinations or agitation but are unable to exhibit aberrant motor behavior. If the clinician or the caregiver believes that the questions are inappropriate, then the section should be marked NA (upper right corner of each section), and no further data are recorded for that section. Likewise, if the clinician feels that the responses are invalid (e.g., the caregiver did not seem to understand the particular set of questions asked), NA should also be marked.

F. Neurovegetative Changes

Items 11 (sleep) and 12 (appetite) were added after the original publication of the NPI (Cummings et al, 1994). They were included because they are common problem areas in Alzheimer's disease and other dementias. They form part of the depression syndrome in some patients and were specifically excluded from the dysphoria subscale of the NPI in order to allow that subscale to focus on mood symptoms. These two symptoms are usually not included in the total NPI score and may not be included in all protocols.

G. Caregiver Distress (NPI-D)

When each domain is completed and the caregiver has completed the frequency and severity rating, you may want to ask the associated caregiver distress question if your protocol includes the distress assessment. To do this, ask the caregiver how much, if any, "emotional or psychological" distress the behavior he or she just discussed causes him or her (the caregiver). The caregiver must rate his or her own distress on a five point scale from 0 - no distress, 1- minimal, 2 - mild, 3 - moderate, 4 - moderately severe, 5 - very severe or extreme. The distress scale of this instrument was developed by Daniel Kaufer, M.D.

III. Scoring the NPI

Frequency is rated as:

- 1 - Occasionally - less than once per week
- 2 - Often - about once per week
- 3 - Frequently - several times per week but less than every day
- 4 - Very frequently - daily or essentially continuously present

Severity is rated as:

- 1 - Mild - produces little distress in the patient
- 2 - Moderate - more disturbing to the patient but can be redirected by the caregiver
- 3 - Severe - very disturbing to the patient and difficult to redirect

The score for each domain is: domain score = frequency x severity

Distress is scored as:

- 0 - no distress
- 1- minimal
- 2 - mild
- 3 - moderate
- 4 - moderately severe
- 5 - very severe or extreme.

Thus, for each behavioral domain there are four scores:

- Frequency
- Severity
- Total (frequency x severity)
- Caregiver distress

A total NPI score can be calculated by adding the scores of the first 10 domain scores together. In most cases, the two neurovegetative items are not included in the NPI total score. If they are included, specify that the 12 item score is being used rather than the 10 item score. The distress score is not included in the total NPI score. The total distress score is generated by adding together the scores of the first 10 or all 12 items of the NPI distress questions; specify specifically whether the 10 or 12 item score is being used.

IV. NPI-NH and NPI-Q

A nursing home version of the NPI (the NPI-NH) has been developed for use with professional caregivers in institutional settings. The instrument is identical to the original NPI but the questions have been rephrased to reflect the fact that the professional caregiver will not have known the patient prior to the onset of the illness and cannot know if the current behaviors represent changes from premorbid behaviors. The caregiver distress questions have been rephrased to assess the “occupational disruptiveness” of the behaviors.

The NPI-Q version of the NPI has been developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in clinical practice settings.

The NPI-NH and NPI-Q are available through the UCLA Alzheimer's Disease Center, Reed Neurological Research Center, 710 Westwood Plaza, Los Angeles, California, 90095-1769.

V. Instructional Videotapes

Instructional videotapes (English language) demonstrating the use of the NPI (for interviewers) and the NPI-NH (one for interviewers and one for interviewees) are available through the UCLA Alzheimer's Disease Center, Reed Neurological Research Center, 710 Westwood Plaza, Los Angeles, California, 90095-1769. The cost of each videotape is \$25.00 (US) (subject to change). Use of the videotapes to train users and achieve uniform application of the NPI or NPI-NH is strongly encouraged if the instruments are to be used for research purposes.

VI. Translations

The NPI is available in a variety of languages for Asia, Europe, and the Americas, and more translated versions are currently being developed. Please correspond with Dr. Cummings at the address shown below (section VIII) regarding the availability of these translations. All translations went through a process of translation and back translation by a bilingual clinician-scientist whose first language was that of the translation. The translator is identified for correspondence when the translation is provided.

VII. Electronic Versions

The NPI, NPI-NH, and NPI-Q are available on disc (no electronically scored or administered version is available) for MacIntosh computers. The disc version can be obtained by contacting Dr. Cummings at the address shown below (section VIII).

VIII. Copyright and Use

The NPI, NPI-NH, and NPI-Q, and all translations and derivations are under copyright protection with all rights reserved to Jeffrey L. Cummings. They are made available at no charge for all noncommercial research and clinical purposes. Use of the NPI, NPI-NH or NPI-Q for commercial purposes (clinical trials, screening for commercial projects, application by for-profit health care providers, etc) is subject to charge and use of the instrument must be negotiated with Dr. Cummings at the UCLA Alzheimer's Disease Center, Reed Neurological Research Center, 710 Westwood Plaza, Los Angeles, California, USA 90095-1769 (telephone 310/206-5238; FAX 310/206-5287; e-mail jcumplings@mednet.ucla.edu).

It is requested that a copy of all published papers and abstracts using the NPI, NPI-NH or NPI-Q be provided to Dr. Cummings at the address shown above. This allows construction of a comprehensive bibliography of studies and investigators using these instruments.

References

- Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology* 1994; 44: 2308-2314.
- Cummings JL. The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients. *Neurology* 1997; 48 (Suppl. 6): S10-S16.
- Kaufner DI, Cummings JL, Christine D, Bray T, Castellon S, Masterman D, MacMillan A, Ketchel P, Dekosky ST. Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: the Neuropsychiatric Inventory Caregiver Distress Scale. *J Am Geriatric Soc* 1998; 46: 210-215.
- Wood S, Cummings JL, Hsu M-A, Barclay T, Wheatley MV, Yarema KT, Schnelle JF. The use of the Neuropsychiatric Inventory in nursing home residents: characterization and measurement. *Am J Geriatr Psychiatry* 1999;8:75-83.

Acknowledgments: UCLA Alzheimer's Disease Center, Academic Geriatric Resource Program, UCLA Center on Aging and the Irving and Helga Cooper Geriatric Research Award; Sidell-Kagan Research Foundation.

A. Delusions

(NA)

Does the patient have beliefs that you know are not true (for example, insisting that people are trying to harm him/her or steal from him/her)? Has he/she said that family members are not who they say they are or that the house is not their home? I'm not asking about mere suspiciousness; I am interested if the patient is convinced that these things are happening to him/her.

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient believe that he/she is in danger - that others are planning to hurt him/her? _____
- 2. Does the patient believe that others are stealing from him/her? _____
- 3. Does the patient believe that his/her spouse is having an affair? _____
- 4. Does the patient believe that unwelcome guests are living in his/her house? _____
- 5. Does the patient believe that his/her spouse or others are not who they claim to be? _____
- 6. Does the patient believe that his/her house is not his/her home? _____
- 7. Does the patient believe that family members plan to abandon him/her? _____
- 8. Does the patient believe that television or magazine figures are actually present in the home? [Does he/she try to talk or interact with them?] _____
- 9. Does the patient believe any other unusual things that I haven't asked about? _____

If the screening question is confirmed, determine the frequency and severity of the delusions.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - once or more per day.

- Severity:
- 1. Mild - delusions present but seem harmless and produce little distress in the patient.
 - 2. Moderate - delusions are distressing and disruptive.
 - 3. Marked - delusions are very disruptive and are a major source of behavioral disruption. [If PRN medications are prescribed, their use signals that the delusions are of marked severity.]

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

B. Hallucinations

(NA)

Does the patient have hallucinations such as seeing false visions or hearing imaginary voices? Does he/she seem to see, hear or experience things that are not present? By this question we do not mean just mistaken beliefs such as stating that someone who has died is still alive; rather we are asking if the patient actually has abnormal experiences of sounds or visions.

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient describe hearing voices or act as if he/she hears voices? _____
- 2. Does the patient talk to people who are not there? _____
- 3. Does the patient describe seeing things not seen by others or behave as if he/she is seeing things not seen by others (people, animals, lights, etc)? _____
- 4. Does the patient report smelling odors not smelled by others? _____
- 5. Does the patient describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her? _____
- 6. Does the patient describe tastes that are without any known cause? _____
- 7. Does the patient describe any other unusual sensory experiences? _____

If the screening question is confirmed, determine the frequency and severity of the hallucinations.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - once or more per day.

- Severity:
- 1. Mild - hallucinations are present but harmless and cause little distress for the patient.
 - 2. Moderate - hallucinations are distressing and are disruptive to the patient.
 - 3. Marked - hallucinations are very disruptive and are a major source of behavioral disturbance. PRN medications may be required to control them.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

C. Agitation/Aggression

(NA)

Does the patient have periods when he/she refuses to cooperate or won't let people help him/her? Is he/she hard to handle?

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient get upset with those trying to care for him/her or resist activities such as bathing or changing clothes? _____
- 2. Is the patient stubborn, having to have things his/her way? _____
- 3. Is the patient uncooperative, resistive to help from others? _____
- 4. Does the patient have any other behaviors that make him hard to handle? _____
- 5. Does the patient shout or curse angrily? _____
- 6. Does the patient slam doors, kick furniture, throw things? _____
- 7. Does the patient attempt to hurt or hit others? _____
- 8. Does the patient have any other aggressive or agitated behaviors? _____

If the screening question is confirmed, determine the frequency and severity of the agitation.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than daily.
 - 4. Very frequently - once or more per day.

- Severity:
- 1. Mild - behavior is disruptive but can be managed with redirection or reassurance.
 - 2. Moderate - behaviors are disruptive and difficult to redirect or control.
 - 3. Marked - agitation is very disruptive and a major source of difficulty; there may be a threat of personal harm. Medications are often required.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

D. Depression/Dysphoria

(NA)

Does the patient seem sad or depressed? Does he/she say that he/she feels sad or depressed?

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient have periods of tearfulness or sobbing that seem to indicate sadness? _____
- 2. Does the patient say or act as if he/she is sad or in low spirits? _____
- 3. Does the patient put him/herself down or say that he/she feels like a failure? _____
- 4. Does the patient say that he/she is a bad person or deserves to be punished? _____
- 5. Does the patient seem very discouraged or say that he/she has no future? _____
- 6. Does the patient say he/she is a burden to the family or that the family would be better off without him/her? _____
- 7. Does the patient express a wish for death or talk about killing him/herself? _____
- 8. Does the patient show any other signs of depression or sadness? _____

If the screening question is confirmed, determine the frequency and severity of the depression.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - essentially continuously present.

- Severity:
- 1. Mild - depression is distressing but usually responds to redirection or reassurance.
 - 2. Moderate - depression is distressing, depressive symptoms are spontaneously voiced by the patient and difficult to alleviate.
 - 3. Marked - depression is very distressing and a major source of suffering for the patient.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

E. Anxiety

(NA)

Is the patient very nervous, worried, or frightened for no apparent reason? Does he/she seem very tense or fidgety? Is the patient afraid to be apart from you?

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient say that he/she is worried about planned events? _____
- 2. Does the patient have periods of feeling shaky, unable to relax, or feeling excessively tense? _____
- 3. Does the patient have periods of [or complain of] shortness of breath, gasping, or sighing for no apparent reason other than nervousness? _____
- 4. Does the patient complain of butterflies in his/her stomach, or of racing or pounding of the heart in association with nervousness? [Symptoms not explained by ill health] _____
- 5. Does the patient avoid certain places or situations that make him/her more nervous such as riding in the car, meeting with friends, or being in crowds? _____
- 6. Does the patient become nervous and upset when separated from you [or his/her caregiver]? [Does he/she cling to you to keep from being separated?] _____
- 7. Does the patient show any other signs of anxiety? _____

If the screening question is confirmed, determine the frequency and severity of the anxiety.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - once or more per day.

- Severity:
- 1. Mild - anxiety is distressing but usually responds to redirection or reassurance.
 - 2. Moderate - anxiety is distressing, anxiety symptoms are spontaneously voiced by the patient and difficult to alleviate.
 - 3. Marked - anxiety is very distressing and a major source of suffering for the patient.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

F. Elation/Euphoria

(NA)

Does the patient seem too cheerful or too happy for no reason? I don't mean the normal happiness that comes from seeing friends, receiving presents, or spending time with family members. I am asking if the patient has a persistent and abnormally good mood or finds humor where others do not.

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient appear to feel too good or to be too happy, different from his/her usual self? _____
- 2. Does the patient find humor and laugh at things that others do not find funny? _____
- 3. Does the patient seem to have a childish sense of humor with a tendency to giggle or laugh inappropriately (such as when something unfortunate happens to others)? _____
- 4. Does the patient tell jokes or make remarks that have little humor for others but seem funny to him/her? _____
- 5. Does he/she play childish pranks such as pinching or playing "keep away" for the fun of it? _____
- 6. Does the patient "talk big" or claim to have more abilities or wealth than is true? _____
- 7. Does the patient show any other signs of feeling too good or being too happy? _____

If the screening question is confirmed, determine the frequency and severity of the elation/euphoria.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - essentially continuously present.

- Severity:
- 1. Mild - elation is notable to friends and family but is not disruptive.
 - 2. Moderate - elation is notably abnormal.
 - 3. Marked - elation is very pronounced; patient is euphoric and finds nearly everything to be humorous.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

G. Apathy/Indifference

(NA)

Has the patient lost interest in the world around him/her? Has he/she lost interest in doing things or does he/she lack motivation for starting new activities? Is he/she more difficult to engage in conversation or in doing chores? Is the patient apathetic or indifferent?

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient seem less spontaneous and less active than usual? _____
- 2. Is the patient less likely to initiate a conversation? _____
- 3. Is the patient less affectionate or lacking in emotions when compared to his/her usual self? _____
- 4. Does the patient contribute less to household chores? _____
- 5. Does the patient seem less interested in the activities and plans of others? _____
- 6. Has the patient lost interest in friends and family members? _____
- 7. Is the patient less enthusiastic about his/her usual interests? _____
- 8. Does the patient show any other signs that he/she doesn't care about doing new things? _____

If the screening question is confirmed, determine the frequency and severity of the apathy/indifference.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - nearly always present.

- Severity:
- 1. Mild - apathy is notable but produces little interference with daily routines; only mildly different from patient's usual behavior; patient responds to suggestions to engage in activities.
 - 2. Moderate - apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaneously only to powerful events such as visits from close relatives or family members.
 - 3. Marked - apathy is very evident and usually fails to respond to any encouragement or external events.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

H. Disinhibition

(NA)

Does the patient seem to act impulsively without thinking? Does he/she do or say things that are not usually done or said in public? Does he/she do things that are embarrassing to you or others?

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient act impulsively without appearing to consider the consequences? _____
- 2. Does the patient talk to total strangers as if he/she knew them? _____
- 3. Does the patient say things to people that are insensitive or hurt their feelings? _____
- 4. Does the patient say crude things or make sexual remarks that he/she would not usually have said? _____
- 5. Does the patient talk openly about very personal or private matters not usually discussed in public? _____
- 6. Does the patient take liberties or touch or hug others in way that is out of character for him/her? _____
- 7. Does the patient show any other signs of loss of control of his/her impulses? _____

If the screening question is confirmed, determine the frequency and severity of the disinhibition.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - essentially continuously present.

- Severity:
- 1. Mild - disinhibition is notable but usually responds to redirection and guidance.
 - 2. Moderate - disinhibition is very evident and difficult to overcome by the caregiver.
 - 3. Marked - disinhibition usually fails to respond to any intervention by the caregiver, and is a source of embarrassment or social distress.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

I. Irritability/Lability

(NA)

Does the patient get irritated and easily disturbed? Are his/her moods very changeable? Is he/she abnormally impatient? We do not mean frustration over memory loss or inability to perform usual tasks; we are interested to know if the patient has abnormal irritability, impatience, or rapid emotional changes different from his/her usual self.

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient have a bad temper, flying “off the handle” easily over little things? _____
- 2. Does the patient rapidly change moods from one to another, being fine one minute and angry the next? _____
- 3. Does the patient have sudden flashes of anger? _____
- 4. Is the patient impatient, having trouble coping with delays or waiting for planned activities? _____
- 5. Is the patient cranky and irritable? _____
- 6. Is the patient argumentative and difficult to get along with? _____
- 7. Does the patient show any other signs of irritability? _____

If the screening question is confirmed, determine the frequency and severity of the irritability/lability.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - essentially continuously present.

- Severity:
- 1. Mild - irritability or lability is notable but usually responds to redirection and reassurance.
 - 2. Moderate - irritability and lability are very evident and difficult to overcome by the caregiver.
 - 3. Marked - irritability and lability are very evident, they usually fail to respond to any intervention by the caregiver, and they are a major source of distress.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

J. Aberrant Motor Behavior

(NA)

Does the patient pace, do things over and over such as opening closets or drawers, or repeatedly pick at things or wind string or threads?

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient pace around the house without apparent purpose? _____
- 2. Does the patient rummage around opening and unpacking drawers or closets? _____
- 3. Does the patient repeatedly put on and take off clothing? _____
- 4. Does the patient have repetitive activities or "habits" that he/she performs over and over? _____
- 5. Does the patient engage in repetitive activities such as handling buttons, picking, wrapping string, etc? _____
- 6. Does the patient fidget excessively, seem unable to sit still, or bounce his/her feet or tap his/her fingers a lot? _____
- 7. Does the patient do any other activities over and over? _____

If the screening question is confirmed, determine the frequency and severity of the aberrant motor activity:

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - essentially continuously present.

- Severity:
- 1. Mild - abnormal motor activity is notable but produces little interference with daily routines.
 - 2. Moderate - abnormal motor activity is very evident; can be overcome by the caregiver.
 - 3. Marked - abnormal motor activity is very evident, usually fails to respond to any intervention by the caregiver, and is a major source of distress.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

K. Sleep

(NA)

Does the patient have difficulty sleeping (do not count as present if the patient simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? Is he/she up at night? Does he/she wander at night, get dressed, or disturb your sleep?

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Does the patient have difficulty falling asleep? _____
- 2. Does the patient get up during the night (do not count if the patient gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? _____
- 3. Does the patient wander, pace, or get involved in inappropriate activities at night? _____
- 4. Does the patient awaken you during the night? _____
- 5. Does the patient awaken at night, dress, and plan to go out thinking that it is morning and time to start the day? _____
- 6. Does the patient awaken too early in the morning (earlier than was his/her habit)? _____
- 7. Does the patient sleep excessively during the day? _____
- 8. Does the patient have any other nighttime behaviors that bother you that we haven't talked about? _____

If the screening question is confirmed, determine the frequency and severity of the nighttime behavior disturbance.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - once or more per day (every night)

- Severity:
- 1. Mild - nighttime behaviors occur but they are not particularly disruptive.
 - 2. Moderate - nighttime behaviors occur and disturb the patient and the sleep of the caregiver; more than one type of nighttime behavior may be present.
 - 3. Marked - nighttime behaviors occur; several types of nighttime behavior may be present; the patient is very distressed during the night and the caregiver's sleep is markedly disturbed.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely

L. Appetite and eating disorders

(NA)

Has he/she had any change in appetite, weight, or eating habits (count as NA if the patient is incapacitated and has to be fed)? Has there been any change in type of food he/she prefers?

NO (If no, proceed to next screening question). YES (If yes, proceed to subquestions).

- 1. Has he/she had a loss of appetite? _____
- 2. Has he/she had an increase in appetite? _____
- 3. Has he/she had a loss of weight? _____
- 4. Has he/she gained weight? _____
- 5. Has he/she had a change in eating behavior such as putting too much food in his/her mouth at once? _____
- 6. Has he/she had a change in the kind of food he/she likes such as eating too many sweets or other specific types of food? _____
- 7. Has he/she developed eating behaviors such as eating exactly the same types of food each day or eating the food in exactly the same order? _____
- 8. Have there been any other changes in appetite or eating that I haven't asked about? _____

If the screening question is confirmed, determine the frequency and severity of the changes in eating habits or appetite.

- Frequency:
- 1. Occasionally - less than once per week.
 - 2. Often - about once per week.
 - 3. Frequently - several times per week but less than every day.
 - 4. Very frequently - once or more per day or continuously

- Severity:
- 1. Mild - changes in appetite or eating are present but have not led to changes in weight and are not disturbing
 - 2. Moderate - changes in appetite or eating are present and cause minor fluctuations in weight.
 - 3. Marked - obvious changes in appetite or eating are present and cause fluctuations in weight, are embarrassing, or otherwise disturb the patient.

- Distress: How emotionally distressing do you find this behavior?
- 0. Not at all
 - 1. Minimally
 - 2. Mildly
 - 3. Moderately
 - 4. Severely
 - 5. Very severely or extremely