

Identification number Assessment Date Number of visits: Number of breaks:	Location seen: Caregiver information obtained from: Length of visit:
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Primary Care physician name:
 Address:
 Specialist name:.....
 Address:
 Last appointment with specialist:.....
 Date of Birth:
 Marital status:
 Years in full-time education:
 Patient at start of visit (during UPDRS-II): **ON / OFF?**
 Did patient have motor fluctuations during visit? **Y/N?**
 Please enter the percentage of fluctuations:

Diagnosis: ☐ PD Date of diagnosis:/...../.....
☐ Other diagnoses (please list all, note year of onset if available):

Detail of Treatment-record all current medication

Medication Name	Dose	Morning					Noon					Evening					Bedtime			
		6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24

Record time of last Parkinsonian medication taken (approx. minutes before assessment):

Current treatments

	Drug	mg/d
<input type="checkbox"/> L-Dopa	<input type="checkbox"/> L-dopa/benserazide	
	<input type="checkbox"/> L-dopa/carbidopa	
	<input type="checkbox"/> L-dopa/carbidopa/entacapone	
	<input type="checkbox"/> Duodopa	
	<input type="checkbox"/> Other :	
<input type="checkbox"/> Dopamine Agonist	<input type="checkbox"/> Bromocriptine	
	<input type="checkbox"/> Pramipexole	
	<input type="checkbox"/> Ropinirole	
	<input type="checkbox"/> Piribedil	
	<input type="checkbox"/> Rotigotine	
	<input type="checkbox"/> Apomorphine, pen	
	<input type="checkbox"/> Apomorphine, pump	
	<input type="checkbox"/> Other :	
<input type="checkbox"/>	<input type="checkbox"/> Rasagiline	

IMAOB	<input type="checkbox"/>	selegiline	
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	Drug	mg/d
<input type="checkbox"/>	Entacapone	
<input type="checkbox"/> ICOMT	Tolcapone	
<input type="checkbox"/>	Anticholinergic name	
<input type="checkbox"/>	Amantadine	
<input type="checkbox"/>	DBS	<input type="checkbox"/> STN <input type="checkbox"/> GPI <input type="checkbox"/> Thal
<input type="checkbox"/>	Antidepressant	
<input type="checkbox"/>	Anxiolytic	
<input type="checkbox"/>	Hypnotic	
<input type="checkbox"/>	Psychostimulant	
<input type="checkbox"/>	Clozapine	
<input type="checkbox"/>	Quetiapine	
<input type="checkbox"/>	Other :	

Has seen in the last 6 months: ☐ Neurologist ☐ Geriatrician ☐ Palliative care specialist ☐ Other physician, speciality:
☐ Nurse ☐ Secretary ☐ CRA ☐ Physiotherapist ☐ Speech therapist ☐ Occupational therapist ☐ Neuropsychologist
☐ Psychologist ☐ Social worker ☐ Other:

CLaSP study: Symptoms and treatment checklist

Identification number

Assessment Date

Clinical problems identified

Motor complications	<input type="checkbox"/> yes	<input type="checkbox"/> no
Motor fluctuations	<input type="checkbox"/>	<input type="checkbox"/>
On-off	<input type="checkbox"/>	<input type="checkbox"/>
Wearing off	<input type="checkbox"/>	<input type="checkbox"/>
Dystonia	<input type="checkbox"/>	<input type="checkbox"/>
Unpredictable off	<input type="checkbox"/>	<input type="checkbox"/>
Dose failures	<input type="checkbox"/>	<input type="checkbox"/>
Dyskinesias	<input type="checkbox"/>	<input type="checkbox"/>

Axial signs	<input type="checkbox"/> yes	<input type="checkbox"/> no
Falls, post. instability	<input type="checkbox"/>	<input type="checkbox"/>
Freezing	<input type="checkbox"/>	<input type="checkbox"/>
Camptocormia	<input type="checkbox"/>	<input type="checkbox"/>
Dysarthria	<input type="checkbox"/>	<input type="checkbox"/>
Swallowing problems	<input type="checkbox"/>	<input type="checkbox"/>

Autonomic failure	<input type="checkbox"/> yes	<input type="checkbox"/> no
Gastrointestinal	<input type="checkbox"/>	<input type="checkbox"/>
Genitourinary	<input type="checkbox"/>	<input type="checkbox"/>
Cardiovascular	<input type="checkbox"/>	<input type="checkbox"/>

Pain (in line with PD)	<input type="checkbox"/> yes	<input type="checkbox"/> no
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Noiceptive	<input type="checkbox"/>	<input type="checkbox"/>
Neuropathic	<input type="checkbox"/>	<input type="checkbox"/>

Sleep disturbances	<input type="checkbox"/> yes	<input type="checkbox"/> no
Excessive daytime sleepn.	<input type="checkbox"/>	<input type="checkbox"/>
Insomnia	<input type="checkbox"/>	<input type="checkbox"/>
RBD	<input type="checkbox"/>	<input type="checkbox"/>
RLS	<input type="checkbox"/>	<input type="checkbox"/>
PLMS	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Apnoea	<input type="checkbox"/>	<input type="checkbox"/>

Cognitive impairment	<input type="checkbox"/> yes	<input type="checkbox"/> no
Apathy	<input type="checkbox"/>	<input type="checkbox"/>
Dementia	<input type="checkbox"/>	<input type="checkbox"/>
Hallucinations	<input type="checkbox"/>	<input type="checkbox"/>

Psychiatric symptoms	<input type="checkbox"/> yes	<input type="checkbox"/> no
Depression	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>
Psychosis	<input type="checkbox"/>	<input type="checkbox"/>

Impulse control disorders	<input type="checkbox"/> yes	<input type="checkbox"/> no
Gambling	<input type="checkbox"/>	<input type="checkbox"/>
Compulsive buying	<input type="checkbox"/>	<input type="checkbox"/>
Hypersexuality	<input type="checkbox"/>	<input type="checkbox"/>
Bingeeating	<input type="checkbox"/>	<input type="checkbox"/>
Punding	<input type="checkbox"/>	<input type="checkbox"/>
Other :	<input type="checkbox"/>	<input type="checkbox"/>

DDS	<input type="checkbox"/> yes	<input type="checkbox"/> no
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Hoehn & Yahr	OFF	ON
Unilateral	①	①
Bilateral, no instability	②	②
Bilateral, some instability	③	③
Severe disability	④	④
Bedridden/wheelchair	⑤	⑤

Scale scores	Cs	HDJ	CMD	Hospitalisation
UPDRS-ADL	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Emergency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Systematic follow-up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Expert (referral)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Treatment adjustment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Complication of PD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Botulinum toxin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Patient education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Academic research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Industrial research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> duration:

Recommendations

Medications adjustments	increase	decrease	start	stop	name
Levodopa	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Dopamine agonist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Apomorphine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
MAO-B inhibitor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Amantadine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
COMT inhibitor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Anticholinergic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Botulinum toxin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Antidepressant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Anxiolytic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Hypnotic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Quetiapine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Antiemetic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Laxative/macrogol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Antimuscarinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
(bladder control)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Conazepam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Fludrocortisone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Referral to	yes	no	Already ongoing
Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
OT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SLT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist/counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Memory clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care of the Elderly physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Botulinum toxin clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palliative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
care/geriatric/other referral	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PDSN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

CLaSP study :

UPDRS Phase II	_____	_____ - _____ - _____	_____	_____
	Site ID	(mm-dd-yyyy) Assessment Date	Investigator's Initials	Daily Sequence Number

Old UPDRS Score Sheet

Part I: Mentation, Behavior, and Mood			3.5b	Rigidity- RUE	_____
1.1	Intellectual impairment	_____	3.5c	Rigidity- LUE	_____
1.2	Thought disorder	_____	3.5d	Rigidity- RLE	_____
1.3	Depression	_____	3.5e	Rigidity- LLE	_____
1.4	Motivation/initiative	_____	3.6a	Finger taps – Right hand	_____
Part II: Activities of Daily Living			3.6b	Finger taps– Left hand	_____
2.1	Speech	_____	3.7a	Hand movements – Right hand	_____
2.2	Salivation	_____	3.7b	Hand movements – Left hand	_____
2.3	Swallowing	_____	3.8a	Rapid movements- Right hand	_____
2.4	Handwriting	_____	3.8b	Rapid movements – Left hand	_____
2.5	Cutting food and handling utensils	_____	3.9a	Leg agility – Right leg	_____
2.6	Dressing	_____	3.9b	Leg agility – Left leg	_____
2.7	Hygiene	_____	3.10	Arising from chair	_____
2.8	Turning in bed and adjusting bedclothes	_____	3.11	Posture	_____
2.9	Falling	_____	3.12	Gait	_____
2.10	Freezing when walking	_____	3.13	Postural stability	_____
2.11	Walking	_____	3.14	Body bradykinesia and Hypokinesia	_____
2.12	Tremor	_____	3.15	Hoehn and Yahr Stage	_____
2.13	Sensory complaints	_____	Part IV: Complications of Therapy		
PART III: Motor Examination			4.1	Duration	_____
3.1	Speech	_____	4.2	Disability	_____
3.2	Facial Expression	_____	4.3	Painful dyskinesias	_____
3.3a	Tremor at rest- Face, lips, chin	_____	4.4	Presence of early morning dystonia	_____
3.3b	Tremor at rest- Right hand	_____	4.5	Are any off periods predictable?	_____
3.3c	Tremor at rest- Left hand	_____	4.6	Are any off periods unpredictable?	_____
3.3d	Tremor at rest- Right foot	_____	4.7	Do any off periods come on suddenly?	_____
3.3e	Tremor at rest- Left foot	_____	4.8	What proportion of the waking day is the participant off?	_____
3.4a	Action or postural tremor– Right hand	_____	4.9	Anorexia, nausea, or vomiting?	_____
3.4b	Action or postural tremor– Left hand	_____	4.10	Sleep disturbances?	_____
3.5a	Rigidity- Neck	_____	4.11	Symptomatic orthostasis?	_____

Participant ID:

Date:

1.6 FEATURES OF DOPAMINE DYSREGULATION SYNDROME

SCORE

Instructions to examiner: Consider involvement in a variety of activities including atypical or excessive gambling (e.g. casinos or lottery tickets), atypical or excessive sexual drive or interests (e.g., unusual interest in pornography, masturbation, sexual demands on partner), other repetitive activities (e.g. hobbies, dismantling objects, sorting or organizing), or taking extra non-prescribed medication for non-physical reasons (i.e., addictive behavior). Rate the impact of such abnormal activities/behaviors on the patient's personal life and on his family and social relations (including need to borrow money or other financial difficulties like withdrawal of credit cards, major family conflicts, lost time from work, or missed meals or sleep because of the activity).

Instructions to patients [and caregiver]: Over the past week, have you had unusually strong urges that are hard to control? Do you feel driven to do or think about something and find it hard to stop? [Give patient examples such as gambling, cleaning, using the computer, taking extra medicine, obsessing about food or sex, all depending on the patients.

- 0: Normal: No problems present.
- 1: Slight: Problems are present but usually do not cause any difficulties for the patient or family/caregiver.
- 2: Mild: Problems are present and usually cause a few difficulties in the patient's personal and family life.
- 3: Moderate: Problems are present and usually cause a lot of difficulties in the patient's personal and family life.
- 4: Severe: Problems are present and preclude the patient's ability to carry out normal activities or social interactions or to maintain previous standards in personal and family life.

Please record participants blood pressure:

- | | | | |
|---|---|--|---|
| 1. Blood pressure
(lying) | systolic
<input type="text"/> (mmHG) | diastolic
<input type="text"/> (mmHG) | <input type="checkbox"/> Tick if taken sitting instead of lying |
| 2. Blood pressure
(standing after three minutes) | <input type="text"/> (mmHG) | <input type="text"/> (mmHG) | |

Identification number

Assessment Date

V. Modified Hoehn and Yahr Staging. Please enter on UPDRS score sheet, section 3.15.

Stage 0—No signs of disease.

Stage 1—Unilateral disease.

Stage 1.5—Unilateral plus axial involvement.

Stage 2—Bilateral disease, without impairment of balance.

Stage 2.5—Mild bilateral disease with recovery on pull test.

Stage 3—Mild to moderate bilateral disease; some postural instability; physically independent.

Stage 4—Severe disability; still able to walk or stand unassisted.

Stage 5—Wheelchair bound or bedridden unless aided.

VI. Modified Schwab and England Activities of Daily Living Scale. Please note down the rating below.

100%—Completely independent. Able to do all chores without slowness, difficulty, or impairment. Essentially normal. Unaware of any difficulty.

90%—Completely independent. Able to do all chores with some degree of slowness, difficulty, and impairment. Might take twice as long. Beginning to be aware of difficulty.

80%—Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness.

70%—Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.

60%—Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible.

50%—More dependent. Help with half, slower, etc. Difficulty with everything.

40%—Very dependent. Can assist with all chores, but few alone.

30%—With effort, now and then does a few chores alone or begins alone. Much help needed.

20%—Nothing alone. Can be a slight help with some chores. Severe invalid.

10%—Total dependent, helpless. Complete invalid.

0%—Vegetative functions such as swallowing, bladder and bowel functions are not functioning. Bedridden.

Schwab and England score : _____

Identification number
Assessment Date

MINI-MENTAL STATE EXAMINATION

ORIENTATION

Max. (Score)

5 () What is the (year)(season)(date)(day)(month)? 1 point for each correct.

5 () Where are we: (state)(county)(town)(hospital)(floor)? 1 point for each correct.

REGISTRATION

3 () Name 3 objects, take 1 second to say each. Then ask the participant to name all 3 after you have said them. *Give 1 point for each correct answer.* Then repeat them until he/she learns all 3. Count trials and record.

Trials taken to learn: _____

ATTENTION AND CALCULATION

5 () Ask the patient to count back in sevens from 100. Stop after 5 answers (93, 86, 79, 72, 65). **Alternatively**, ask participant to **spell** the word 'world' backwards. Award 1 point for each correct answer.

RECALL

3 () Ask for the 3 objects repeated above under 'Registration'. Award one point for each correct answer.

LANGUAGE

2 () Show the participant two objects (a pencil and a watch) and ask them to identify and name these. (2 points)

1 () Ask the participant to repeat: 'No ifs, ands, or buts' (1 point)

3 () Ask the participants to follow a (3-stage) command: 'Take a paper in your right hand, fold it in half, and put it on the floor.' Award a point for each command successfully followed.

Ask the participant to read and obey the following written commands:

1 () Close your eyes (1 point)

1 () Write a sentence (1 point)

1 () Copy design (angles must intersect properly as shown)(1 point)

End of MMSE. Total Score: _____

ASSESS level of consciousness along a continuum _____

Alert drowsy stupor coma

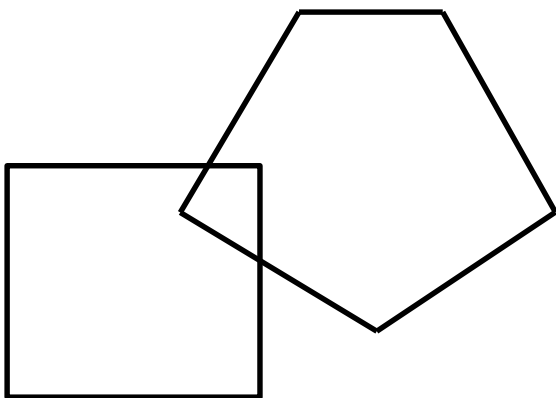
Participant ID:

Date: .

CLOSE AND OPEN YOUR EYES!

WRITE A SENTENCE!

COPY THIS DESIGN!



Non-Motor Symptom assessment scale for Parkinson's Disease

Patient ID No: _____

Initials: _____

Age: _____

Symptoms assessed over the last month. Each symptom scored with respect to:

Severity: 0 = None, 1 = Mild: symptoms present but causes little distress or disturbance to patient; 2 = Moderate: some distress or disturbance to patient; 3 = Severe: major source of distress or disturbance to patient.

Frequency: 1 = Rarely (<1/wk); 2 = Often (1/wk); 3 = Frequent (several times per week); 4 = Very Frequent (daily or all the time)

Domains will be weighed differentially. Yes/ No answers are not included in final frequency x severity calculation. (Bracketed text in questions within the scale is included as an explanatory aid).

Domain 1: Cardiovascular including falls

1. Does the patient experience light-headedness, dizziness, weakness on standing from sitting or lying position?

Severity

Frequency

Frequency
x Severity

☐
☐
☐

2. Does the patient fall because of fainting or blacking out?

☐
☐
☐

SCORE:

Domain 2: Sleep/fatigue

3. Does the patient doze off or fall asleep unintentionally during daytime activities? (For example, during conversation, during mealtimes, or while watching television or reading).

☐
☐
☐

4. Does fatigue (tiredness) or lack of energy (not slowness) limit the patient's daytime activities?

☐
☐
☐

5. Does the patient have difficulties falling or staying asleep?

☐
☐
☐

6. Does the patient experience an urge to move the legs or restlessness in legs that improves with movement when he/she is sitting or lying down inactive?

☐
☐
☐

SCORE:

Domain 3: Mood /Cognition

7. Has the patient lost interest in his/her surroundings?

☐
☐
☐

8. Has the patient lost interest in doing things or lack motivation to start new activities?

☐
☐
☐

9. Does the patient feel nervous, worried or frightened for no apparent reason?

☐
☐
☐

10. Does the patient seem sad or depressed or has he/she reported such feelings?

☐
☐
☐

11. Does the patient have flat moods without the normal "highs" and "lows"?

☐
☐
☐

12. Does the patient have difficulty deriving pleasure from their usual activities or report that they lack pleasure?

☐
☐
☐

SCORE:

Domain 4: Perceptual problems/hallucinations

13. Does the patient indicate that he/she sees things that are not there?

☐
☐
☐

14. Does the patient have beliefs that you know are not true? (For example, about being harmed, being robbed or being unfaithful)

☐
☐
☐

15. Does the patient experience double vision? (2 separate real objects and not blurred vision)

☐
☐
☐

SCORE:

Date:

<u>Severity</u>	<u>Frequency</u>	<u>Frequency x Severity</u>
1	1	1
2	1	2
3	1	3
4	1	4
5	1	5
6	1	6
7	1	7
8	1	8
9	1	9
10	1	10
11	1	11
12	1	12
13	1	13
14	1	14
15	1	15
16	1	16
17	1	17
18	1	18
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120	1	120
121	1	121
122	1	122
123	1	123
124	1	124
125	1	125
126	1	126
127	1	127
128	1	128
129	1	129
130	1	130
131	1	131
132	1	132
133	1	133

Domain 5: Attention/ Memory

16. Does the patient have problems sustaining concentration during activities? (For example, reading or having a conversation)
17. Does the patient forget things that he/she has been told a short time ago or events that happened in the last few days?
18. Does the patient forget to do things? (For example, take tablets or turn off domestic appliances?)

A 3x3 grid of squares. The top two rows are complete, each containing three squares. The bottom row contains two squares, with the rightmost position empty.

Domain 6: Gastrointestinal tract

19. Does the patient dribble saliva during the day?
20. Does the patient having difficulty swallowing?
21. Does the patient suffer from constipation?
(Bowel action less than three times weekly)

Domain 7: Urinary

22. Does the patient have difficult _____)
23. Does the patient have to void within 2 hours of last voiding? (Frequency)
24. Does the patient have to get up regularly at night to pass urine? (Nocturia)

Domain 8: Sexual function

25. Does the patient have altered interest in sex?
(Very much increased or decreased, please underline)
26. Does the patient have problems having sex?

Domain 9: Miscellaneous

27. Does the patient suffer from pain not explained by other known conditions? (Is it related to intake of drugs and is it relieved by antiparkinson drugs?)
28. Does the patient report a change in ability to taste or smell?
29. Does the patient report a recent change in weight (not related to dieting)?
30. Does the patient experience excessive sweating? (not related to hot weather)

TOTAL SCORE:

Developed by the International Parkinson's Disease Non-Motor Group.
Contacts: ray.chaudhuri@uhl.nhs.uk or alison.forbes@uhl.nhs.uk

Clock drawing

Instructions to investigator: *Ensure the participant has a pen and a table/clipboard in front of them. Predraw a circle on an A4 sheet of paper (to minimize the effect of education and motor impairment or use the worksheet provided overleaf).*

Ask the participant: *'Place the numbers on the circle to make it look like a clock. Then place the hands to read ten past two.'*

Cutoff: *Bring the task to an end if the participant is unable to insert the correct clock face numbers or draw the hands. Score according to the scoresheet attached.*

Clock drawing score:	1	2	3	4	5	6	7	8	9	10
-----------------------------	---	---	---	---	---	---	---	---	---	----

Method for evaluating clock drawings described by Sunderland and colleagues¹⁴

Score

Criterion

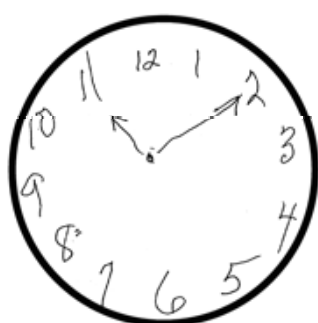
10–6 Drawing of clock face with circle and number is generally intact.

- 10 Hands are in correct position.
- 9 Slight errors in placement of the hands.
- 8 More noticeable errors in the placement of hour and minute hands.
- 7 Placement of hands is significantly off course.
- 6 Inappropriate use of clock hands (i.e., use of digital display or circling of numbers despite repeated instructions).

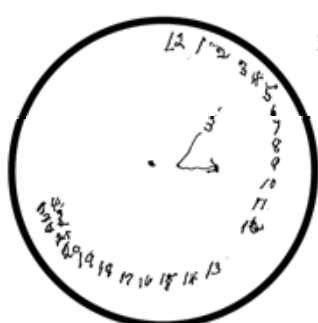
5–1 Drawing of clock face with circle and numbers is *not* intact.

- 5 Crowding of numbers at one end of the clock or reversal of numbers. Hands may still be present in some fashion.
- 4 Further distortion of number sequence. Integrity of clock face is now gone (i.e., numbers missing or placed at outside of the boundaries of the clock face).
- 3 Numbers and clock face no longer obviously connected in the drawing. Hands are not present.
- 2 Drawing reveals some evidence of instructions being received but only a vague representation of a clock.
- 1 Either no attempt or an uninterpretable effort is made.

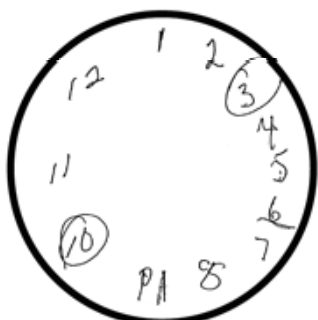
Scores



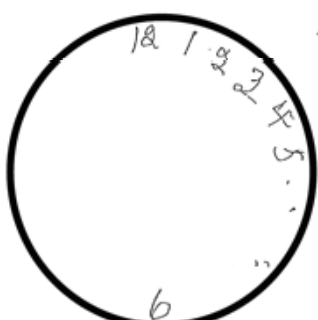
10



5



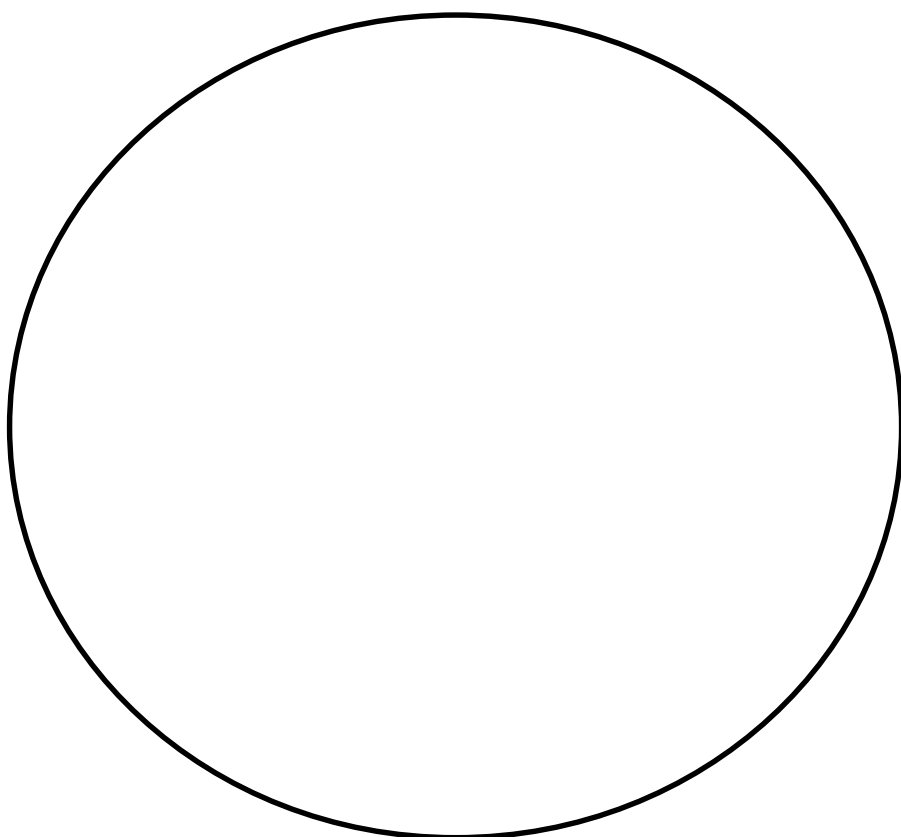
6



4

Participant ID:

Date: .



CLaSP study :

Identification number	Assessment Date
-----------------------	-----------------

Lexical Fluency

Instructions to investigator: *Have a clock ready to keep track of time (60 seconds). Ask the participant: 'List as many words beginning with the letter 'S' as you can. I will st*

Count the number of words in 1 minute (exclude duplications, names). Use this sheet for any notes to keep track if necessary. (A score ≤ 9 words is considered as an impairment.)

Lexical fluency score (number of words listed):	
--	--

The Geriatric Depression Scale (GDS)

*By: Sherry A. Greenberg, PhD(c), MSN, GNP-BC,
Hartford Institute for Geriatric Nursing, NYU College of Nursing*

WHY: Depression is common in late life, affecting nearly 5 million of the 31 million Americans aged 65 and older with clinically significant depressive symptoms reaching 13% in older adults aged 80 and older (Blazer, 2009). Major depression is reported in 8-16% of community dwelling older adults, 5-10% of older medical outpatients seeing a primary care provider, 10-12% of medical-surgical hospitalized older adults with 23% more experiencing significant depressive symptoms (Blazer, 2009). Recognition in long-term care facilities is poor and not consistent amongst studies (Blazer, 2009).

Depression is not a natural part of aging. Depression is often reversible with prompt recognition and appropriate treatment. However, if left untreated, depression may result in the onset of physical, cognitive, functional, and social impairment, as well as decreased quality of life, delayed recovery from medical illness and surgery, increased health care utilization, and suicide.

BEST TOOL: While there are many instruments available to measure depression, the Geriatric Depression Scale (GDS), first created by Yesavage, et al., has been tested and used extensively with the older population. The GDS Long Form is a brief, 30-item questionnaire in which participants are asked to respond by answering yes or no in reference to how they felt over the past week. A Short Form GDS consisting of 15 questions was developed in 1986. Questions from the Long Form GDS which had the highest correlation with depressive symptoms in validation studies were selected for the short version. Of the 15 items, 10 indicated the presence of depression when answered positively, while the rest (question numbers 1, 5, 7, 11, 13) indicated depression when answered negatively. Scores of 0-4 are considered normal, depending on age, education, and complaints; 5-8 indicate mild depression; 9-11 indicate moderate depression; and 12-15 indicate severe depression.

The Short Form is more easily used by physically ill and mildly to moderately demented patients who have short attention spans and/or feel easily fatigued. It takes about 5 to 7 minutes to complete.

TARGET POPULATION: The GDS may be used with healthy, medically ill and mild to moderately cognitively impaired older adults. It has been extensively used in community, acute and long-term care settings.

VALIDITY AND RELIABILITY: The GDS was found to have a 92% sensitivity and a 89% specificity when evaluated against diagnostic criteria. The validity and reliability of the tool have been supported through both clinical practice and research. In a validation study comparing the Long and Short Forms of the GDS for self-rating of symptoms of depression, both were successful in differentiating depressed from non-depressed adults with a high correlation ($r = .84, p < .001$) (Sheikh & Yesavage, 1986).

STRENGTHS AND LIMITATIONS: The GDS is not a substitute for a diagnostic interview by mental health professionals. It is a useful screening tool in the clinical setting to facilitate assessment of depression in older adults especially when baseline measurements are compared to subsequent scores. It does not assess for suicidality.

FOLLOW-UP: The presence of depression warrants prompt intervention and treatment. The GDS may be used to monitor depression over time in all clinical settings. Any positive score above 5 on the GDS Short Form should prompt an in-depth psychological assessment and evaluation for suicidality.

MORE ON THE TOPIC:

Best practice information on care of older adults: www.ConsultGerIRN.org.

The Stanford/VA/NIA Aging Clinical Resource Center (ACRC) website. Retrieved July 2, 2012, from <http://www.stanford.edu/~yesavage/ACRC.html>. Information on the GDS. Retrieved July 2, 2012, from <http://www.stanford.edu/~yesavage/GDS.html>.

Blazer, D.G. (2009). Depression in late life: Review and commentary. *FOCUS*, 7(1), 118-136.

Greenberg, S.A. (2007). How to Try This: The Geriatric Depression Scale: Short Form. *AJN*, 107(10), 60-69.

Harvath, T.A., & McKenzie, G. (2012). Depression in Older Adults. In M. Boltz, E. Capezuti, T.T. Fulmer, & D. Zwicker (Eds.), A. O'Meara (Managing Ed.), *Evidence-based geriatric nursing protocols for best practice* (4th ed., pp. 135-162). NY: Springer Publishing Company, LLC.

Koenig, H.G., Meador, K.G., Cohen, J.J., & Blazer, D.G. (1988). Self-rated depression scales and screening for major depression in the older hospitalized patient with medical illness. *JAGS*, 36, 699-706.

Sheikh, J.I., & Yesavage, J.A. (1986). Geriatric Depression Scale (GDS). Recent evidence and development of a shorter version. In T.L. Brink (Ed.), *Clinical Gerontology: A Guide to Assessment and Intervention* (pp. 165-173). NY: The Haworth Press, Inc.

Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O., Huang, V., Adey, M.B., & Leirer, V.O. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17, 37-49.

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Geriatric Depression Scale: Short Form

Choose the best answer for how you have felt over the past week:

1. Are you basically satisfied with your life? YES / **NO**
2. Have you dropped many of your activities and interests? **YES** / NO
3. Do you feel that your life is empty? **YES** / NO
4. Do you often get bored? **YES** / NO
5. Are you in good spirits most of the time? YES / **NO**
6. Are you afraid that something bad is going to happen to you? **YES** / NO
7. Do you feel happy most of the time? YES / **NO**
8. Do you often feel helpless? **YES** / NO
9. Do you prefer to stay at home, rather than going out and doing new things? **YES** / NO
10. Do you feel you have more problems with memory than most? **YES** / NO
11. Do you think it is wonderful to be alive now? YES / **NO**
12. Do you feel pretty worthless the way you are now? **YES** / NO
13. Do you feel full of energy? YES / **NO**
14. Do you feel that your situation is hopeless? **YES** / NO
15. Do you think that most people are better off than you are? **YES** / NO

Answers in **bold** indicate depression. Score 1 point for each bolded answer.

A score > 5 points is suggestive of depression.

A score ≥ 10 points is almost always indicative of depression.

A score > 5 points should warrant a follow-up comprehensive assessment.

Source: <http://www.stanford.edu/~yesavage/GDS.html>

This scale is in the public domain.

The Hartford Institute for Geriatric Nursing would like to acknowledge the original author of this Try This, Lenore Kurlowicz, PhD, RN, CS, FAAN, who made significant contributions to the field of geropsychiatric nursing and passed away in 2007.



A series provided by The Hartford Institute for Geriatric Nursing,
New York University, College of Nursing

EMAIL hartford.ign@nyu.edu HARTFORD INSTITUTE WEBSITE www.hartfordign.org
CLINICAL NURSING WEBSITE www.ConsultGerIRN.org

Patient ID:

Date:

THE PILL QUESTIONNAIRE:

Ask the participant to describe their prescribed medication, including drug, dose and timings. Consult the carer if necessary. Note the score as appropriate (please circle 0-3 below).

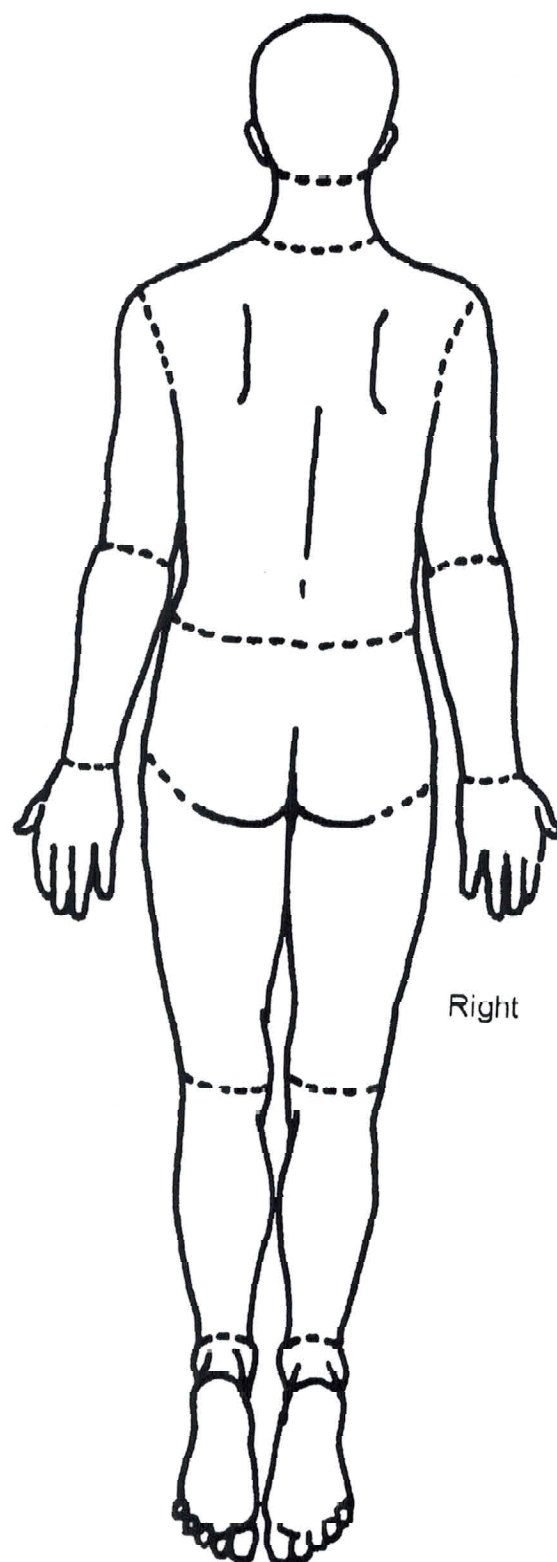
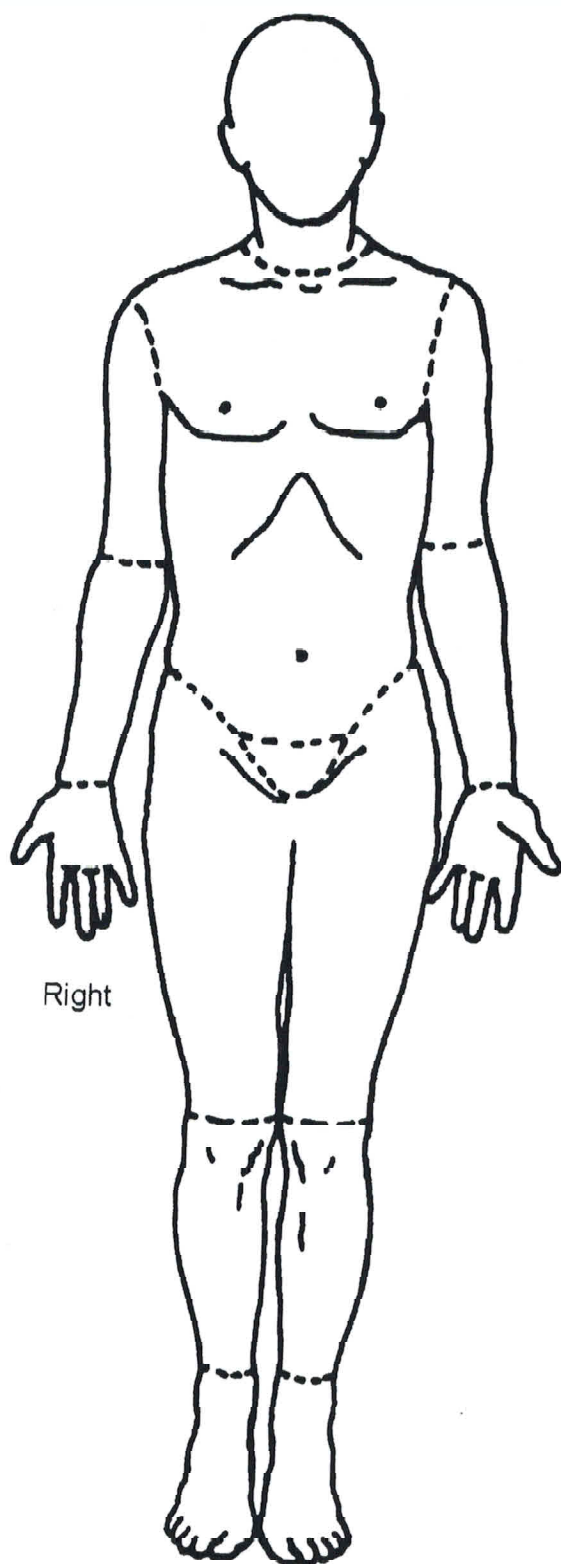
The patient is able to spontaneously and clearly describe the drugs, doses (mg or color of tablet), and timing of treatment = there is no impact.	0
The patient needs some help from the examiner (What time do you take your medication, which drug, which doses ?...) but he/she is successful without clinically pertinent errors. In this case, the determination of impact of daily living requires consultation with a caregiver:	
If the caregiver certifies that the patient can (or could) safely and reliably take the pills without supervision in daily life = no impact.	1
If the caregiver certifies that the patient can (or could) no longer safely and reliably take the pills without supervision in daily life = there is an impact on daily living.	2
The patient is not able to describe, even with the help of the examiner, the time and nature (drugs and doses) of his/her treatment = impact on daily living.	3

Edmonton Symptom Assessment System - PD

Patient ID:

Date:

Please mark on these pictures where is it you hurt.



Edmonton Symptom Assessment System (ESAS)

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name _____

Date _____ Time _____

Complete by (*check one*)

☐ Patient

☐ Caregiver

☐ Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

August, 2006

Used with permission from the Regional Palliative Care Program, Capital Health, Edmonton, Alberta, 2006

Participant ID:

Date:

PARKINSON'S DISEASE SYMPTOM ASSESSMENT

No Stiffness

0 1 2 3 4 5 6 7 8 9 10

Worst Possible Stiffness

No Constipation

0 1 2 3 4 5 6 7 8 9 10

Worst Possible Constipation

No Swallowing
Difficulties

0 1 2 3 4 5 6 7 8 9 10

Worst Possible Swallowing

No Confusion

0 1 2 3 4 5 6 7 8 9 10

Worst Possible Confusion

Patient ID:

Date:

Charlson score: http://touchcalc.com/calculators/ccl_is - on line calculator [accessed June 13th, 2013]

Charlson Comorbidity Index

(<http://www.fpnotebook.com/prevent/Exam/ChrlsnCmrbdtyIndx.htm>)

Aka: Charlson Comorbidity Index, Comorbidity-Adjusted Life Expectancy

1. Indication
 1. Assess whether a patient will live long enough to benefit from a specific screening measure or medical intervention
2. Scoring: Comorbidity Component (Apply 1 point to each unless otherwise noted)
 1. Myocardial Infarction
 2. Congestive Heart Failure
 3. Peripheral Vascular Disease
 4. Cerebrovascular Disease
 5. Dementia
 6. COPD
 7. Connective Tissue Disease
 8. Peptic Ulcer Disease
 9. Diabetes Mellitus (1 point uncomplicated, 2 points if end-organ damage)
 10. Moderate to Severe Chronic Kidney Disease (2 points)
 11. Hemiplegia (2 points)
 12. Leukemia (2 points)
 13. Malignant Lymphoma (2 points)
 14. Solid Tumor (2 points, 6 points if metastatic)
 15. Liver Disease (1 point mild, 3 points if moderate to severe)
 16. AIDS (6 points)
3. Scoring: Age
 1. Age <40 years: 0 points
 2. Age 41-50 years: 1 points
 3. Age 51-60 years: 2 points
 4. Age 61-70 years: 3 points
 5. Age 71-80 years: 4 points
4. Interpretation
 1. Calculate Charlson Score or Index (i)
 1. Add Comorbidity score to age score
 2. Total denoted as 'i' below
 2. Calculate Charlson Probability (10 year mortality)
 1. Calculate $Y = e^{(i * 0.9)}$
 2. Calculate $Z = 0.983^Y$
 3. where Z is the 10 year survival
5. References
 1. [Charlson \(1987\) J Chron Dis 40: 373-83](#)
 2. [Gold \(1994\) J Clin Epidemiol 47: 1245-51](#)

Patient ID:

Date:

CGI – Clinical Global Impressions scale

The questions are asked 3 times – Participant's opinion, carer's opinion, investigator's opinion.

CGI-severity overall

Read out the question and all seven answer options. Circle the answers in the appropriate box below.

How well has the participant been during the week preceding this visit?

- 1 = normal, not at all ill
- 2 = borderline ill
- 3 = mildly ill
- 4 = moderately ill
- 5 = markedly ill
- 6 = severely ill
- 7 = extremely ill

Participant:							Carer:							Investigator:						
1	2	3	4	5	6	7	1	2	3	4	5	6	7	1	2	3	4	5	6	7

CGI-Change (T2, T3, T4 only)

Read out the question and all seven answer options. Circle the answers in the appropriate box below.

Compared to the last visit, how much has the participant's health changed?

- 1 = Marked improvement
- 2 = Moderate improvement
- 3 = Minimal improvement
- 4 = No change
- 5 = Minimal worsening
- 6 = Moderate worsening
- 7 = Marked worsening

Participant:							Carer:							Investigator:						
1	2	3	4	5	6	7	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Patient ID:

Date:

Economic Questionnaire

CLaSP – Care of Late Stage Parkinsonism

1 Course of illness and Resource Use

1.1 In what year was your Parkinson's disease diagnosed?

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
y	y	y	y

1.2 Is the doctor looking after your Parkinson's disease a General Practitioner or a neurologist?

<input type="checkbox"/>	General Practitioner
<input type="checkbox"/>	Neurologist
<input type="checkbox"/>	Both do
<input type="checkbox"/>	Not known

1.3 How often did you consult your primary care physician for Parkinson's disease during the past 3 months?

Number of visits

<input type="text"/>	<input type="text"/>	visits
----------------------	----------------------	--------

1.4 How often did you consult your neurologist/geriatrician for Parkinson's disease during the past 3 months?

Number of visits

<input type="text"/>	<input type="text"/>	visits
----------------------	----------------------	--------

1.5 Did you consult further doctors/specialists about your Parkinson's disease in the last 3 months (in addition to seeing your primary Parkinson's physician)?

Physician / Specialist	Number of visits
<input type="checkbox"/> Urologist	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Psychiatrist	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Ear, nose and throat specialist	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Dermatologist	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Radiologist	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Psychologist	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Dentist	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Parkinson's disease nurse	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Specialist in _____	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Specialist in _____	<input type="text"/> <input type="text"/> visits
<input type="checkbox"/> Specialist in _____	<input type="text"/> <input type="text"/> visits

1.6 Did you receive further therapy (apart from medication) during the past 3 months due to Parkinson's disease?

Therapy	Number of visits
<input type="checkbox"/> Physiotherapy	<input type="checkbox"/> <input type="checkbox"/> visits
<input type="checkbox"/> Massage	<input type="checkbox"/> <input type="checkbox"/> visits
<input type="checkbox"/> Occupational therapy	<input type="checkbox"/> <input type="checkbox"/> visits
<input type="checkbox"/> Speech training	<input type="checkbox"/> <input type="checkbox"/> visits
<input type="checkbox"/> Nurse	<input type="checkbox"/> <input type="checkbox"/> visits
<input type="checkbox"/> Counselling	<input type="checkbox"/> <input type="checkbox"/> visits
<input type="checkbox"/> others, which ones	<input type="checkbox"/> <input type="checkbox"/> visits

Inpatient treatment in hospital

1.7 Were you treated as an inpatient in hospitals during the past 3 months (at least one night) due to Parkinson's disease? If so, please indicate the reason and the length of the hospital stay.

Reason for hospital stay	Was your hospitalisation related to Parkinson's disease?		Length of stay (e.g. 10 nights)
	Yes	No	
			___ days
			___ days
			___ days

1.8 Did you stay at an inpatient (overnight) rehabilitation facility during the past 3 months?

- ☐ No
☐ Yes

1.9 Did you stay at an outpatient (dayhospital) rehabilitation facility during the past 3 months?

- ☐ No
☐ Yes

If "yes", how many days in the last three months did you spend as an inpatient (at least one night) or as an outpatient in a rehabilitation facility? Please do also count the day of admittance and the day of discharge as a full day.

- ☐ Outpatient in rehabilitation facility _____ days
☐ Inpatient in rehabilitation facility _____ days

1.10 What medication prescribed by a physician did you take during the past 3 months?

(Please include all medications, for Parkinson's or not)

Name of the medication

1.11 Did you take any medication during the past 3 months without prescription (not prescribed by a physician and paid for by yourself)?

(Please include all sorts of medication, also e.g. vitamins such as vitamin C, laxatives,)

Name of the medication/vitamins

1.12 Did you receive any of the medical devices listed below during the past 3 months?

- ☐ No, I did not receive any medical devices/consumables during the past 3 months
- ☐ Yes, I did receive medical devices/consumables during the past 3 months:

<u>Medical devices</u>	<u>Number</u>	<u>Did you have to pay some of it?</u>	<u>No</u>	<u>Not known</u>
Walking stick	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>
Frame	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>
Handrail in home	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>
Ramp in home	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>
Wheel-chair	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>
Special bed	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>

Consumables

Toilet seat	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>
Incontinence pads	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>
Catheter equipment	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>
Others_____	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>
Others_____	<input type="checkbox"/>	_____ £	<input type="checkbox"/>	<input type="checkbox"/>

1.13 Were there any other financial burdens due to Parkinson's disease within the past 3 months which were not covered by the questionnaire (e.g. paying for carers, having to take taxis to hospitals)? Please feel free to use this space for your comments.

2 Personal data of the informal PWP

2.1 What is your current employment situation (please check only the most appropriate)?

- ☐ Employee full time
- ☐ Employee part time, _____ hours/week
- ☐ Self-employed
- ☐ Volunteering, starting
- ☐ Unemployed due to Parkinson's disease and its subsequent illnesses, starting
- ☐ Unemployed due to other reasons, starting
- ☐ Early retirement due to Parkinson's disease and its subsequent illnesses, starting
- ☐ Early retirement due to other reasons, starting

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>m</i>	<i>m</i>	<i>y</i>	<i>y</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>m</i>	<i>m</i>	<i>y</i>	<i>y</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>m</i>	<i>m</i>	<i>y</i>	<i>y</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>m</i>	<i>m</i>	<i>y</i>	<i>y</i>

☐ Retired, starting☐ ☐ ☐ ☐
m m y y☐ Housewife☐ Not applicable (n/a)**2.2 If employed or self-employed have you been absent from work during the past 3 months due to Parkinson's disease?**

If you were treated in hospital as an inpatient or were on a rehabilitation clinic please do not include these days

☐ No☐ Yes Number of days*: in 3 Months

* Please also include single hours per working day (e.g. 4 hours = 0.5)

☐ Not applicable (n/a)**2.3 Did you have to change your employment situation due to Parkinson's disease during the last 3 months?**☐ No☐ Yes, I had to stop working☐ Yes, I had to get another job

☐ Yes, I had to reduce my work time from ____ hours/week to ____ hours/week,
since
m m y y

☐ Yes, I had to get another job and to reduce my work time from ____ hours/week to
____ hours/week, since
m m y y

☐ Yes, I had to do an occupational re-training**2.4 Do you have private health insurance or compulsory health insurance?**☐ Private health insurance☐ Compulsory health insurance**2.5 Do you pay anything for your prescription medications?**☐ No☐ Yes**2.6 Do you receive monthly payments e.g. from the compulsory long term care insurance or Disability Living allowance because of Parkinson's disease?**☐ No☐ Yes £ / month

3 Personal data of the informal Caregiver**3.1 What is your relationship to the PWP?**

- ☐ Spouse
☐ Life partner
☐ Daughter
☐ Son
☐ Daughter-in-law
☐ Son-in-law
☐ Friend
☐ Other, please specify _____

3.2 Do you live with the PWP?

- ☐ Yes (if "yes" please continue with question 3.6)
☐ Sometimes
☐ No

3.3 If you don't live together with the PWP all of the time, how often do you visit the PWP?

- ☐ several times every day
☐ once every day
☐ at least once per week
☐ at least once per month
☐ less than once per month
☐ I never visit the PWP

3.4 If you don't live together with the PWP, how often do you talk to the PWP on the phone?

- ☐ several times every day
☐ once every day
☐ at least once per week
☐ at least once per month
☐ less than once per month
☐ I never talk to the PWP on the phone

3.5 If you don't live together with the PWP, for how long are you in contact with the PWP in one week?

- ☐ less than 1 hour
☐ less than 5 hours
☐ 5 to 10 hours
☐ 10 to 24 hours
☐ more than 24 hours

3.6 What is your current employment situation (please check only the most appropriate)?

- ☐ Employee full time
☐ Employee part time, _____ hours/week
☐ Self-employed
☐ Volunteering, starting ☐ ☐ ☐ ☐
m m y y
☐ Unemployed due to the PWP's Parkinson's disease and its subsequent illnesses, ☐ ☐ ☐ ☐
m m y y
☐ Unemployed due to other reasons, starting ☐ ☐ ☐ ☐
m m y y
☐ Early retirement due to the PWP's Parkinson's disease and its subsequent illnesses, ☐ ☐ ☐ ☐
m m y y
☐ Early retirement due to other reasons, starting ☐ ☐ ☐ ☐
m m y y
☐ Retired, starting ☐ ☐ ☐ ☐
m m y y
☐ Housewife
☐ Not applicable (n/a)

3.7 Have you been absent from work during the past 3 months due to care for the PWP?

If you were treated in hospital as an inpatient or were on a rehabilitation clinic please do not include these days

- ☐ No
☐ Yes Number of days*: in 3 Months

* Please also include single hours per working day (e.g. 4 hours = 0.5)

- ☐ Not applicable (n/a)

3.8 Did you have to change your employment situation due to the PWP's Parkinson's disease during the last 3 months?

- ☐ No
☐ Yes, I had to stop working
☐ Yes, I had to get another job
☐ Yes, I had to reduce my work time from ____ hours/week to ____ hours/week,
 since
m m y y
☐ Yes, I had to get another job and to reduce my work time from ____ hours/week to
 ____ hours/week, since
m m y y
☐ Yes, I had to do an occupational re-training

4 PWP's Living and Care Situation

4.1 Please specify the PWP's current living accommodation.

- ☐ Own home
- ☐ With relatives since __ / __ (mm / yy)
- ☐ Intermediate forms of accommodation (e.g. Short term care / Respite care) since __ / __ (mm / yy)
- ☐ Assisted living (accommodation with on site support) since __ / __ (mm / yy)
- ☐ Long-term institutional care (care home with nursing) since __ / __ (mm / yy)
- ☐ Other _____

4.2 If the PWP lives in his/her own home, how many persons live in his/her household permanently? Please include all children living in his/her household.

Person(s)

4.3 Does the PWP need help in his/her daily life from caregivers?

- ☐ No
- ☐ Yes (if "yes", please answer the following questions)

4.4 If the PWP needs help in his/her daily life from caregivers, please specify the assistance he/she needs (check all that apply)?

- ☐ Assistance with dressing
- ☐ Assistance with personal hygiene
- ☐ Assistance with preparing food
- ☐ Assistance with eating
- ☐ Assistance with preparation / intake / application of medication
- ☐ Assistance with the household chores, e.g. shopping, cleaning, DIY, looking after home
- ☐ Assistance with mobility
- ☐ Others _____
- ☐ Others _____

4.5 If the PWP lives in his/her own home, please specify the above care he/she has received during the last 3 months?

- ☐ Informal care (provided by e.g. family members, neighbours, friends) since __ / __ (mm / yy)
- ☐ Professional care (provided by a professional care service) since __ / __ (mm / yy)

If he/she received **professional care**:

How much professional care does he/she receive per week ____ hours / week

- ☐ Financial assistance by state or insurance for home care _____ Euro (no Cents)

Informal care:

4.6 Are there any people (other than yourself) helping with the care of the PWP?

Yes ☐ No ☐ If yes, who? _____

4.7 Among all professional and informal caregivers what proportion of the care do you provide?

- ☐ < 20%
☐ 20 - 40%
☐ 41 - 60%
☐ 61 - 80%
☐ > 80%

4.8 On a typical care day during the last 30 days, how much time per day did you assist the PWP with tasks such as shopping, food preparation, housekeeping, laundry, transportation, taking medication and managing financial matters?

☐ ☐ hours and ☐ ☐ minutes per day

4.9 During the last 30 days, how many days did you spend providing these services to the PWP?

☐ ☐ days

4.10 On a typical care day during the last 30 days, how much time per day did you spend supervising (that is, prevent dangerous events) the PWP?

☐ ☐ hours and ☐ ☐ minutes per day

Professional services

4.11 For each service listed below, please specify the number of days the PWP received the service during the last 3 months.

- ☐ Day Care outside the home (e.g. day centre) _____ days
☐ Day Care inside the home (carer coming to the home) _____ days
☐ Night Care _____ days
☐ Respite or Short-term Care admission _____ days
☐ Nursing home _____ days
☐ Other _____

4.12 For each service listed below, please specify the number of times the service was used during the last 3 months.

- ☐ Food delivery (meals on wheels / food delivery by supermarkets) _____ times/week
☐ Transportation (care related) _____ times
☐ Support group / Self-help group _____ times
☐ Other _____ times

Patient ID:

Date:

Neuropsychiatric Inventory Questions

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.

☐ Yes (If yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient believe that he/she is in danger - that others are planning to hurt him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient believe that others are stealing from him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient believe that his/her spouse is having an affair? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient believe that unwelcome guests are living in his/her house? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient believe that his/her spouse or others are not who they claim to be? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient believe that his/her house is not his/her home? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient believe that family members plan to abandon him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 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?) | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 9. Does the patient believe any other unusual things that I haven't asked about? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely — less than once per week
- ☐ 2. Sometimes — about once per week
- ☐ 3. Often — several times per week but less than every day
- ☐ 4. Very often — 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. Severe — 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

B. HALLUCINAIONS**(NA)**

Does the patient have hallucinations such as seeing false visions or hearing false 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.

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient describe hearing voices or act as if he/she hears voices? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient talk to people who are not there? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does he/she describe seeing things not seen by others or behave as if he/she is seeing things not seen by others (people, animals, lights, etc)? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does he/she report smelling odors not smelled by others? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does he/she describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does he/she describe tastes that are without any known cause? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does he/she describe any other unusual sensory experiences? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – 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. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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?

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

1. Does the patient get upset with those trying to care for him/her or resist activities such as bathing or changing clothes?

☐ Yes

☐ No

2. Is the patient stubborn, having to have things his/her way?

☐ Yes

☐ No

3. Is the patient uncooperative, resistive to help from others?

☐ Yes

☐ No

4. Does the patient have any other behaviors that make him/her hard to handle?

☐ Yes

☐ No

5. Does the patient shout or curse angrily?

☐ Yes

☐ No

6. Does the patient slam doors, kick furniture, throw things?

☐ Yes

☐ No

7. Does the patient attempt to hurt or hit others?

☐ Yes

☐ No

8. Does the patient have any other aggressive or agitated behaviors?

☐ Yes

☐ No

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

Frequency:

☐ 1. Rarely – less than once per week.

☐ 2. Sometimes – about once per week.

☐ 3. Often – several times per week but less than every day.

☐ 4. Very often – once or more per day.

Severity:

☐ 1. Mild – agitation is disruptive but can be managed with redirection or reassurance.

☐ 2. Moderate – agitation is disruptive and difficult to redirect or control.

☐ 3. Severe – 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 (almost no change in work routine)

☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)

☐ 3. Moderately (disrupts work routine, requires time rebudgeting)

☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

D. DEPRESSION/DYSPHORIA**(NA)**

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

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

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

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – 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. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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?

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient say that he/she is worried about planned events? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient have periods of feeling shaky, unable to relax, or feeling excessively tense? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient have periods of [or complain of] shortness of breath, gasping, or sighing for no apparent reason other than nervousness? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 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) | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 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? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 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?) | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient show any other signs of anxiety? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – 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. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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.

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient appear to feel too good or to be too happy, different from his/her usual self? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient find humor and laugh at things that others do not find funny? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 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)? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient tell jokes or make remarks that are not funny to others but seem funny to him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does he/she play childish pranks such as pinching or playing "keep away" for the fun of it? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient "talk big" or claim to have more abilities or wealth than is true? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient show any other signs of feeling too good or being too happy? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – essentially continuously present.

Severity:

- ☐ 1. Mild – elation is notable to friends and family but is not disruptive.
- ☐ 2. Moderate – elation is notably abnormal.
- ☐ 3. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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?

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient seem less spontaneous and less active than usual? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Is the patient less likely to initiate a conversation? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Is the patient less affectionate or lacking in emotions when compared to his/her usual self? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient contribute less to household chores? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient seem less interested in the activities and plans of others? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Has the patient lost interest in friends and family members? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Is the patient less enthusiastic about his/her usual interests? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Does the patient show any other signs that he/she doesn't care about doing new things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – 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. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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?

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient act impulsively without appearing to consider the consequences? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient talk to total strangers as if he/she knew them? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient say things to people that are insensitive or hurt their feelings? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient say crude things or make sexual remarks that he/she would not usually have said? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient talk openly about very personal or private matters not usually discussed in public? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient take liberties or touch or hug others in way that is out of character for him/her? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient show any other signs of loss of control of his/her impulses? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – 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. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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.

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient have a bad temper, "flying off the handle" easily over little things? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient rapidly change moods from one to another, being fine one minute and angry the next? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient have sudden flashes of anger? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Is the patient impatient, having trouble coping with delays or waiting for planned activities? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Is the patient cranky and irritable? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Is the patient argumentative and difficult to get along with? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient show any other signs of irritability? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – 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. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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?

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|--|------------------------------|-----------------------------|
| 1. Does the patient pace around the house without apparent purpose? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Does the patient rummage around opening and unpacking drawers or closets? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient repeatedly put on and take off clothing? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient have repetitive activities or "habits" that he/she performs over and over? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient engage in repetitive activities such as handling buttons, picking, wrapping string, etc? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient fidget excessively, seem unable to sit still, or bounce his/her feet or tap his/her fingers a lot? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient do any other activities over and over? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – 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. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

K. SLEEP AND NIGHTTIME BEHAVIOR DISORDERS**(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?

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Does the patient have difficulty falling asleep? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 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)? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Does the patient wander, pace, or get involved in inappropriate activities at night? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Does the patient awaken you during the night? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Does the patient wake up at night, dress, and plan to go out, thinking that it is morning and time to start the day? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Does the patient awaken too early in the morning (earlier than was his/her habit)? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Does the patient sleep excessively during the day? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Does the patient have any other nighttime behaviors that bother you that we haven't talked about? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – 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. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

L. APPETITE AND EATING CHANGES**(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?

☐ Yes (if yes, please proceed to subquestions)

☐ No (if no, please proceed to next screening question)

☐ N/A

- | | | |
|---|------------------------------|-----------------------------|
| 1. Has he/she had a loss of appetite? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Has he/she had an increase in appetite? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Has he/she had a loss of weight? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Has he/she gained weight? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Has he/she had a change in eating behavior such as putting too much food in his/her mouth at once? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 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? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 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? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Have there been any other changes in appetite or eating that I haven't asked about? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

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

Frequency:

- ☐ 1. Rarely – less than once per week.
- ☐ 2. Sometimes – about once per week.
- ☐ 3. Often – several times per week but less than every day.
- ☐ 4. Very often – 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. Severe – 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 (almost no change in work routine)
- ☐ 2. Mildly (almost no change in work routine but little time rebudgeting required)
- ☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
- ☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

NPI

Neuropsychiatric Inventory

Scoring Summary

CENTER #	SCREENING #	PATIENT #	PATIENT INITIALS	VISIT	DATE
<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> F M L	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> M D Y

Please transcribe appropriate categories from the NPI Worksheet into the boxes provided.

For each domain:

- If symptoms of a domain did not apply, check the "N/A" box.
- If symptoms of a domain were absent, check the "0" box.
- If symptoms of a domain were present, check one score each for Frequency and Severity.
- **Multiply** Frequency score x Severity score and enter the product in the space provided.
- Total all Frequency x Severity scores and record the Total Score below.
- If symptoms of a domain were present, check one score for Distress; total all distress scores for a summary score.

Rater's
Initials:

DOMAIN	N/A ¹	ABSENT	FREQUENCY	SEVERITY	FREQUENCY X SEVERITY	CAREGIVER DISTRESS
		0	1 2 3 4	1 2 3		0 1 2 3 4 5
A. Delusions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
B. Hallucinations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
C. Agitation/Aggression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
D. Depression/Dysphoria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
E. Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
F. Elation/Euphoria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
G. Apathy/Indifference	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
H. Disinhibition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
I. Irritability/Lability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
J. Aberrant Motor Behavior	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
TOTAL SCORE:					<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
K. Sleep and Nighttime Behavior Disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
L. Appetite/Eating Changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>