Summary of Patient < 3y at Visit 10 (72 months)

Clinician Scoring	Page	Direct online data entry available?
Medication	316	Yes
BPW	320	Yes
Diagnostic Features	321	Yes
UPDRS Clinician	326	Yes
L-Dopa Challenge	328	Yes
UPDRS Clinician	337	Yes
MoCA	340	No
Blood Tests	348	Yes

Note: MoCA to be done with the patient on paper, and can then be copied to online

Patient Questionnaires	Page
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Medication

Current drugs

Tick here if completed directly online (you can leave the sheet blank) ☐

Antiparkinson drugs (mark one or more)

- ☐ L-dopa (including Stalevo)
- ☐ Amantadine
- ☐ Anticholinergic
- ☐ COMT-I
- ☐ Dopamine agonist
- ☐ MAOB-I
- ☐ None
- ☐ Other (specify below)

L-Dopa

Leave blank if patient is not on L-dopa.

- ☐ Co-beneldopa
- ☐ Co-careldopa
- ☐ Controlled release (CR) or similar
- ☐ Other (specify below)
- ☐ Dispersible
- ☐ Madopar or similar
- ☐ Sinemet or similar
- ☐ Stalevo

L-Dopa times per day

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ >7

Number of different times L-dopa is taken daily.

Tick once data is copied from this page to online ☐

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For a guide to L-dopa doses, see V7 Medication form.

Tick here if completed directly online (you can leave the sheet blank) ☐

Enter the unit dose of L-dopa taken, e.g. Sinemet Plus 1 tab 3x daily is 100 in each of the first 3 boxes.

1st L-dopa	2nd L-dopa	3rd L-dopa	4th L-dopa
5th L-dopa	**6th L-dopa**	**7th L-dopa**	**Additional L-dopa**

Include irregular doses, estimate an average if necessary.

Amantadine

unit dose (mg)	times per day (amantadine)	any extra

Anticholinergic (mark one or more)

		unit dose			
☐	Trihexyphenidyl (Benzhexol)		mg		times per day
☐	Procyclidine		mg		times per day
☐	Other (specify below)		mg		times per day

COMT-I (ignore Stalevo here)

		unit dose			
☐	Entacapone		mg		times per day
☐	Tolcapone		mg		times per day
☐	Other (specify below)		mg		times per day

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Dopamine agonists

Tick here if completed directly online (you can leave the sheet blank) ☐

		unit dose			
☐	Apomorphine intermittent		mg		times per day
☐	Apomorphine pump	mg per hour			hours per day
☐	Bromocriptine		mg		times per day
☐	Cabergoline		mg		times per day
☐	Pergolide		mg		times per day
☐	Pramipexole (Standard or PR)		mg		times per day
☐	Salt		mg		times per day
☐	Base		mg		times per day

(Ignore system rounding for Pramipexole)

☐	Ropinirole (Standard or XL)		mg		times per day
☐	Rotigotine		mg		times per day
☐	Other (specify below)		mg		times per day

☐

MAOB-I

		unit dose			
☐	Rasagiline		mg		times per day
☐	Selegiline		mg		times per day
☐	Zelapar		mg		times per day
☐	Other (specify below)		mg		times per day

☐

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Tick here if completed directly online (you can leave the sheet blank)

Other Medication

Record drugs taken, other than direct antiparkinson drugs, below.

Include supporting therapy for PD here, e.g. domperidone, etc.

How many drugs (other than direct antiparkinson drugs)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

☐ 8 ☐ 9 ☐ 10 ☐ 11 ☐ 12 ☐ >12

Record additional medications in the Memo field online.

Number of different times L-dopa is taken daily.

Name

drug 1

Name

drug 2

Name

drug 3

Name

drug 4

Name

drug 5

Name

drug 6

Name

drug 7

Name

drug 8

Name

drug 9

Name

drug 10

Name

drug 11

Name

drug 12

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Blood Pressure, Pulse, Weight

Tick here if completed directly online (you can leave the sheet blank)

Lying BP and pulse

Check the patient's blood pressure and pulse after at least 3 minutes lying as flat as they can manage comfortably

Systolic BP (lying)

Diastolic BP (lying)

Pulse rate (lying)

Standing BP and pulse

Stand the patient upright and measure their blood pressure and pulse after 2 minutes of standing

Systolic BP (standing)

Diastolic BP (standing)

Pulse rate (standing)

Weight

Enter in your choice of units

Enter weight in which units?

- Metric
- Imperial

Weight in kg

Stones

Pounds

Tick once data is copied from this page to online

Diagnostic Features

Tick here if completed directly online (you can leave the sheet blank)

(Questions 1 - 3 are deliberately omitted at this visit)

Please note if any of the following are present

4. Unusual or atypical course of disease:
- Yes
- No

4.1 Very rapid progression (to stage III in Hoehn and Yahr classification: Some balance impairment, mild to moderate bilateral disease, physically independent)
- Yes
- No

4.2 Static or little change
- Yes
- No

4.3 Hemiparkinsonism longer than 6 years
- Yes
- No

4.5 Other
- Yes
- No

Specify which other features

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SPECIFIC CLINICAL FEATURES

Tick here if completed directly online (you can leave the sheet blank)

Please mark which of the following are correct in this case

1. Tremor:

1.1 Resting tremor present and typical for PD

Yes

1.2 Resting tremor absent

Yes

1.3 Prominent action tremor

Yes

1.4 Other specific tremor features

Yes

Specify

2. Rigidity

2.1 Rigidity is present and typical for PD

Yes

2.2 Rigidity is absent

Yes

2.3 Axial rigidity in excess of distal rigidity

Yes

2.4 Marked unilateral or asymmetric rigidity

Yes

2.5 Additional type of increased tone (i.e. paratonia, catatonia, spasticity)

Yes

2.6 Other features of rigidity

Yes

No

Specify which features

Tick once data is copied from this page to online

3. Akinesia / Bradykinesia

Tick here if completed directly online (you can leave the sheet blank)

3.1 Bradykinesia is present and typical for PD

- Yes

3.2 Bradykinesia is absent

- Yes

3.3 Pure Akinesia (without rigidity or tremor)

- Yes

3.4 Bradykinesia does not completely account for difficulty with rapid successive movements (e.g. apraxia, ataxia, pyramidal tract dysfunction)

- Yes

3.5 Other features of akinesia / bradykinesia

- Yes
- No

Specify which features

4. Postural or gait disturbances

4.1 Postural and gait disturbances are completely typical of PD

- Yes

4.2 Wide-based gait or ataxia

- Yes

4.3 Prominent freezing early in course

- Yes

4.4 Likely to fall if not extra careful

- Yes

4.5 Other features of postural or gait difficulties

- Yes
- No

Specify which features

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5. Other hyperkinesias (not related to levodopa or agonists):

Tick here if completed directly online (you can leave the sheet blank)

5.1 Dystonia

- Yes

5.2 Chorea

- Yes

5.3 Myoclonus (include stimulus-induced)

- Yes

5.4 Other features of hyperkinesia

- Yes
- No

Specify which features

6. Presence of body hemiatrophy

- Yes

7. Autonomic disturbances:

7.1 Sexual dysfunction (significant change in the past year)

- Yes
- No

7.2 For males only: Ask patient to rate his ability in the previous 3 months, without treatment, to have and maintain an erection adequate for intercourse

- Very poor
- Poor
- Fair
- Good
- Very good

7.3 Urinary dysfunction (significant change in the past year)

- Yes

8. Oculomotor disturbances

- Yes

9. Eyelid disturbances (e.g. "apraxia" of lid opening, blepharospasm)

- Yes

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10. Other neurological abnormalities atypical of parkinsonism

- [ ] Hyperreflexia
- [ ] Babinski sign
- [ ] Sensory deficit
- [ ] Amyotrophy
- [ ] Limb apraxia
- [ ] Sleep apnea
- [ ] Dysmetria
- [ ] Other cerebellar dysfunction

Tick here if completed directly online (you can leave the sheet blank)

11. Little or no response to levodopa or a dopamine agonist

- ◯ Yes
- ◯ No
- ◯ Not applicable (eg. not on L-dopa)

12. Presence of very rapid speech (tachyphemia)

- ◯ Yes

13. Presence of dysphagia or other bulbar dysfunction

- ◯ Yes

Questions 14 and 15 are omitted deliberately

16. Is there anything unusual or atypical about this subject's disease which could indicate an alternative diagnosis to Parkinson's Disease (i.e. idiopathic parkinsonism with the presence of Lewy bodies in the substantia nigra) no matter how remote?

- [ ] Presentation
- [ ] Symptoms
- [ ] Signs
- [ ] Course
- [ ] Response to therapy
- [ ] Other

16.1 Specify what is unusual or atypical

LIKELIHOOD OF DIAGNOSIS

1. Based on all available information, in your opinion, what is the current probability that this individual had idiopathic Parkinson's disease (expressed in %)

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UPDRS Clinician Scoring

Tick here if completed directly online (you can leave the sheet blank)

1.1 Cognitive impairment

0: No cognitive impairment.

1: Slight: Impairment appreciated by patient or caregiver with no concrete interference with the patient's ability to carry out normal activities and social interactions.

2: Mild: Clinically evident cognitive dysfunction, but only minimal interference with the patient's abilities to carry out normal activities and social interactions.

3: Moderate: Cognitive deficits interfere with but do not proclude the patient's ability to carry out normal activities and social interactions.

4: Severe: Cognitive dysfunction precludes the patient's ability to carry out normal activities and social interactions.

1.2 Hallucinations and Psychosis

0: Normal: No hallucinations or psychotic behaviour.

1: Slight: Illusions or non-formed hallucinations, but patient recognizes them without loss of insight.

2: Mild: Formed hallucinations independent of environmental stimuli. No loss of insight.

3: Moderate: Formed hallucinations with loss of insight.

4: Severe: Patient has delusions or paranoia.

1.3 Depressed Mood

0: Normal: No depressed mood.

1: Slight: Episodes of depressed mood that are not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions.

2: Mild: Depressed mood that is sustained over days, but without interference with normal activities and social interactions.

3: Moderate: Depressed mood that interferes with, but does not preclude, the patients ability to carry out normal activities and social interactions.

4: Severe: Depressed mood precludes patient's ability to carry out normal activities and social interactions.

1.4 Anxious Mood

0: Normal: No anxious feelings.

1: Slight: Anxious feelings present but not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions.

2: Mild: Anxious feelings are sustained over more than one day at a time, but without interference with patient's ability to carry out normal activities and social interactions.

3: Moderate: Anxious feelings interfere with, but do not preclude, the patient's ability to carry out normal activities and social interactions.

4: Severe: Anxious feelings preclude patient's ability to carry out normal activities and social interactions.

Tick once data is copied from this page to online

Tick here if completed directly online (you can leave the sheet blank)

1.5 Apathy

- 0: Normal: No apathy.
- 1: Slight: Apathy appreciated by patient and/or caregiver, but no interference with daily activities and social interactions.
- 2: Mild: Apathy interferes with isolated activities and social interactions.
- 3: Moderate: Apathy interferes with most activities and social interactions.
- 4: Severe: Passive and withdrawn, complete loss of initiative.

1.6 Features of Dopamine Dysregulation Syndrome

- 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 presonal 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 inteactions or to maintain previous standards in personal and family life.

Tick once data is copied from this page to online

Did the patient complete the L-Dopa Challenge test at V5?

◯ Yes ◯ No

If yes, record UPDRS in baseline section below, and leave post-dose section blank.

If no, is the patient taking L-dopa based medication?

◯ Yes ◯ No

If yes, complete baseline and post-dose sections.

If no, record UPDRS in baseline section below and leave post-dose section blank.

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L-dopa Challenge Test

Tick here if completed directly online (you can leave the sheet blank)

Scoring

- (•) Baseline
- ( ) Post dose

Time of last L-dopa dose

Hours | Minutes

Time of UPDRS3 recording

Hours | Minutes

3.1 Speech

( )0 ( )1 ( )2 ( )3 ( )4

0: Normal: No speech problems.

1: Slight: Loss of modulation, diction or volume, but still all words easy to understand.

2: Mild: Loss of modulation, diction, or volume, with a few words unclear, but the overall sentences easy to follow.

3: Moderate: Speech is difficult to understand to the point that some, but not most, sentences are poorly understood.

4: Severe: Most speech is difficult to understand or unintelligible.

3.2 Facial expression

( )0 ( )1 ( )2 ( )3 ( )4

0: Normal: Normal facial expression.

1: Slight: Minimal masked facies manifested only by decreased frequency of blinking.

2: Mild: In addition to decreased eye-blink frequency, masked facies present in the lower face as well, namely fewer movements around the mouth, such as less spontaneous smiling, but lips not parted.

3: Moderate: Masked facies with lips parted some of the time when the mouth is at rest.

4: Severe: Masked facies with lips parted most of the time when the mouth is at rest.

3.3 Rigidity

0: Normal: No rigidity.

1: Slight: Rigidity only detected with activation manoeuvre

2: Mild: Rigidity detected without the activation manoeuvre, but full range of motion is easily achieved.

3: Moderate: Rigidity detected without the activation manoeuvre; full range of motion is achieved with effort.

4: Severe: Rigidity detected without the activation manoeuvre and full range of motion not achieved.

3.3a Rigidity Neck
( )0 ( )1 ( )2 ( )3 ( )4

3.3b R arm
( )0 ( )1 ( )2 ( )3 ( )4

3.3c L arm
( )0 ( )1 ( )2 ( )3 ( )4

3.3d R leg
( )0 ( )1 ( )2 ( )3 ( )4

3.3e L leg
( )0 ( )1 ( )2 ( )3 ( )4

Tick once data is copied from this page to online

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3.4 Finger taps, 3.5 Hand movements, and **3.6 Pronation-supination movement of hands**

Tick here if completed directly online (you can leave the sheet blank)

0: Normal: No problems.

1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the tapping movement; b) slight slowing; c) the amplitude decrements near the end of the sequence.

2: Mild: Any of the following: a) 3 to 5 interruptions during tapping; b) mild slowing; c) the amplitude decrements midway in the sequence.

3: Moderate: Any of the following: a) more than 5 interruptions during tapping or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) the amplitude decrements starting after the 1st movement.

4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.

3.4 Finger taps

3.4a R hand
○0 ○1 ○2 ○3 ○4

3.4b L hand
○0 ○1 ○2 ○3 ○4

3.5 Hand movements

3.5a R hand
○0 ○1 ○2 ○3 ○4

3.5b L hand
○0 ○1 ○2 ○3 ○4

3.6 Pronation-supination

3.6a R arm
○0 ○1 ○2 ○3 ○4

3.6b L arm
○0 ○1 ○2 ○3 ○4

3.7 Toe tapping and **3.8 Leg agility**

0: Normal: No problems.

1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) slight slowing; c) amplitude decrements near the end of the task.

2: Mild: Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowness; c) amplitude decrements midway in the task.

3: Moderate: Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing in speed; c) amplitude decrements after the first tap.

4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.

3.7 Toe tapping

3.7a R leg
○ 0 ○ 1 ○ 2 ○ 3 ○ 4

3.7b L leg
○ 0 ○ 1 ○ 2 ○ 3 ○ 4

3.8 Leg agility

3.8a R leg
○ 0 ○ 1 ○ 2 ○ 3 ○ 4

3.8b L leg
○ 0 ○ 1 ○ 2 ○ 3 ○ 4

3.9 Arising from chair

○0 ○1 ○2 ○3 ○4

0: Normal: No problems. Able to arise quickly without hesitation.

1: Slight: Arising is slower than normal; or may need more than one attempt; or may need to move forward in the chair to arise. No need to use the arms of the chair.

2: Mild: Pushes self up from arms of chair without difficulty.

3: Moderate: Needs to push off, but tends to fall back; or may have to try more than one time using arms of chair, but can get up without help.

4: Severe: Unable to arise without help.

3.10 Gait

○0 ○1 ○2 ○3 ○4

0: Normal: No problems.

1: Slight: Independent walking with minor gait impairment.

2: Mild: Independent walking but with substantial gait impairment.

3: Moderate: Requires an assistance device for safe walking (walking stick, walker) but not a person.

4: Severe: Cannot walk at all or only with another person's assistance.

Tick here if completed directly online (you can leave the sheet blank)

3.11 Freezing of Gait

○0 ○1 ○2 ○3 ○4

0: Normal: No freezing.

1: Slight: Freezes on starting, turning or walking through doorway with a single halt during any of these events, but then continues smoothly without freezing during straight walking.

2: Mild: Freezes on starting, turning or walking through doorway with more than one halt during any of these activities, but continues smoothly without freezing during straight walking.

3: Moderate: Freezes once during straight walking.

4: Severe: Freezes multiple times during straight walking.

3.12 Postural Stability

○0 ○1 ○2 ○3 ○4

0: Normal: No problems: Recovers with one or two steps.

1: Slight: 3 - 5 steps, but subject recovers unaided.

2: Mild: More than 5 steps, but subject recovers unaided.

3: Moderate: Stands safely, but with absence of postural response; falls if not caught by examiner.

4: Severe: Very unstable, tends to lose balance spontaneously or with just a gentle pull on the shoulders.

3.13 Posture

○0 ○1 ○2 ○3 ○4

0: Normal: No problems.

1: Slight: Not quite erect, but posture could be normal for older person.

2: Mild: Definite flexion, scoliosis or leaning to one side, but patient can correct posture to normal posture when asked to do so.

3: Moderate: Stooped posture, scoliosis or leaning to one side that cannot be corrected volitionally to a normal posture by the patient.

4: Severe: Flexion, scoliosis or leaning with extreme abnormality of posture.

3.14 Global Spontaneity of Movement (Body Bradykinesia)

○0 ○1 ○2 ○3 ○4

0: Normal: No problems.

1: Slight: Slight global slowness and poverty of spontaneous movements.

2: Mild: Mild global slowness and poverty of spontaneous movements.

3: Moderate: Moderate global slowness and poverty of spontaneous movements.

4: Severe: Severe global slowness and poverty of spontaneous movements.

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Tick here if completed directly online (you can leave the sheet blank)

3.15 Postural tremor of hands, 3.16 Kinetic tremor of hands, 3.17 Rest tremor amplitude

0: Normal: No tremor.

1: Slight: Tremor is present but less than 1 cm in amplitude.

2: Mild: Tremor is at least 1 but less than 3 cm in amplitude (for jaw rest tremor, less than 2cm).

3: Moderate: Tremor is at least 3 but less than 10 cm in amplitude (for jaw rest tremor, less than 3cm).

4: Severe: Tremor is at least 10 cm in amplitude (for jaw rest tremor, more than 3cm).

3.15 Postural tremor of hands

3.15a R hand

○0 ○1 ○2 ○3 ○4

3.15b L hand

○0 ○1 ○2 ○3 ○4

3.16 Kinetic tremor of hands

3.16a R hand

○0 ○1 ○2 ○3 ○4

3.16b L hand

○0 ○1 ○2 ○3 ○4

3.17 Rest tremor amplitude

3.17a Lip/jaw

○0 ○1 ○2 ○3 ○4

3.17b R arm

○0 ○1 ○2 ○3 ○4

3.17c L arm

○0 ○1 ○2 ○3 ○4

3.17d R leg

○0 ○1 ○2 ○3 ○4

3.17e L leg

○0 ○1 ○2 ○3 ○4

3.18 Constancy of Rest Tremor

○0 ○1 ○2 ○3 ○4

0: Normal: No tremor.

1: Slight: Tremor at rest is present < 25% of the entire examination period.

2: Mild: Tremor at rest is present 26 - 50% of the entire examination period.

3: Moderate: Tremor at rest is present 51 - 75% of the entire examination period.

4: Severe: Tremor at rest is present > 75% of the entire examination period.

Were dyskinesias present?

○No ○Yes

Did they interfere with ratings?

○No ○Yes

Patient's clinical state

○Off ○On

Tick once data is copied from this page to online

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L-dopa Challenge Test

Tick here if completed directly online (you can leave the sheet blank)

Scoring

- ○ Baseline
- ◉ Post dose

Time of test L-dopa dose

Hours

Minutes

Time of UPDRS3 recording

Hours

Minutes

3.1 Speech

○0 ○1 ○2 ○3 ○4

0: Normal: No speech problems.

1: Slight: Loss of modulation, diction or volume, but still all words easy to understand.

2: Mild: Loss of modulation, diction, or volume, with a few words unclear, but the overall sentences easy to follow.

3: Moderate: Speech is difficult to understand to the point that some, but not most, sentences are poorly understood.

4: Severe: Most speech is difficult to understand or unintelligible.

3.2 Facial expression

○0 ○1 ○2 ○3 ○4

0: Normal: Normal facial expression.

1: Slight: Minimal masked facies manifested only by decreased frequency of blinking.

2: Mild: In addition to decreased eye-blink frequency, masked facies present in the lower face as well, namely fewer movements around the mouth, such as less spontaneous smiling, but lips not parted.

3: Moderate: Masked facies with lips parted some of the time when the mouth is at rest.

4: Severe: Masked facies with lips parted most of the time when the mouth is at rest.

3.3 Rigidity

0: Normal: No rigidity.

1: Slight: Rigidity only detected with activation manoeuvre

2: Mild: Rigidity detected without the activation manoeuvre, but full range of motion is easily achieved.

3: Moderate: Rigidity detected without the activation manoeuvre; full range of motion is achieved with effort.

4: Severe: Rigidity detected without the activation manoeuvre and full range of motion not achieved.

3.3a Rigidity Neck

○0 ○1 ○2 ○3 ○4

3.3b R arm

○0 ○1 ○2 ○3 ○4

3.3c L arm

○0 ○1 ○2 ○3 ○4

3.3d R leg

○0 ○1 ○2 ○3 ○4

3.3e L leg

○0 ○1 ○2 ○3 ○4

3.4 Finger taps, 3.5 Hand movements, and **3.6 Pronation-supination movement of hands**

Tick here if completed directly online (you can leave the sheet blank)

0: Normal: No problems.

1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the tapping movement; b) slight slowing; c) the amplitude decrements near the end of the sequence.

2: Mild: Any of the following: a) 3 to 5 interruptions during tapping; b) mild slowing; c) the amplitude decrements midway in the sequence.

3: Moderate: Any of the following: a) more than 5 interruptions during tapping or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) the amplitude decrements starting after the 1st movement.

4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.

3.4 Finger taps

3.4a R hand ○0 ○1 ○2 ○3 ○4

3.4b L hand ○0 ○1 ○2 ○3 ○4

3.5 Hand movements

3.5a R hand ○0 ○1 ○2 ○3 ○4

3.5b L hand ○0 ○1 ○2 ○3 ○4

3.6 Pronation-supination

3.6a R arm ○0 ○1 ○2 ○3 ○4

3.6b L arm ○0 ○1 ○2 ○3 ○4

3.7 Toe tapping and **3.8 Leg agility**

0: Normal: No problems.

1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) slight slowing; c) amplitude decrements near the end of the task.

2: Mild: Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowness; c) amplitude decrements midway in the task.

3: Moderate: Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing in speed; c) amplitude decrements after the first tap.

4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.

3.7 Toe tapping

3.7a R leg ○0 ○1 ○2 ○3 ○4

3.7b L leg ○0 ○1 ○2 ○3 ○4

3.8 Leg agility

3.8a R leg ○0 ○1 ○2 ○3 ○4

3.8b L leg ○0 ○1 ○2 ○3 ○4

3.9 Arising from chair

○0 ○1 ○2 ○3 ○4

0: Normal: No problems. Able to arise quickly without hesitation.

1: Slight: Arising is slower than normal; or may need more than one attempt; or may need to move forward in the chair to arise. No need to use the arms of the chair.

2: Mild: Pushes self up from arms of chair without difficulty.

3: Moderate: Needs to push off, but tends to fall back; or may have to try more than one time using arms of chair, but can get up without help.

4: Severe: Unable to arise without help.

3.10 Gait

○0 ○1 ○2 ○3 ○4

0: Normal: No problems.

1: Slight: Independent walking with minor gait impairment.

2: Mild: Independent walking but with substantial gait impairment.

3: Moderate: Requires an assistance device for safe walking (walking stick, walker) but not a person.

4: Severe: Cannot walk at all or only with another person's assistance.

Tick here if completed directly online (you can leave the sheet blank)

3.11 Freezing of Gait

○0 ○1 ○2 ○3 ○4

0: Normal: No freezing.

1: Slight: Freezes on starting, turning or walking through doorway with a single halt during any of these events, but then continues smoothly without freezing during straight walking.

2: Mild: Freezes on starting, turning or walking through doorway with more than one halt during any of these activities, but continues smoothly without freezing during straight walking.

3: Moderate: Freezes once during straight walking.

4: Severe: Freezes multiple times during straight walking.

3.12 Postural Stability

○0 ○1 ○2 ○3 ○4

0: Normal: No problems: Recovers with one or two steps.

1: Slight: 3 - 5 steps, but subject recovers unaided.

2: Mild: More than 5 steps, but subject recovers unaided.

3: Moderate: Stands safely, but with absence of postural response; falls if not caught by examiner.

4: Severe: Very unstable, tends to lose balance spontaneously or with just a gentle pull on the shoulders.

3.13 Posture

○0 ○1 ○2 ○3 ○4

0: Normal: No problems.

1: Slight: Not quite erect, but posture could be normal for older person.

2: Mild: Definite flexion, scoliosis or leaning to one side, but patient can correct posture to normal posture when asked to do so.

3: Moderate: Stooped posture, scoliosis or leaning to one side that cannot be corrected volitionally to a normal posture by the patient.

4: Severe: Flexion, scoliosis or leaning with extreme abnormality of posture.

3.14 Global Spontaneity of Movement (Body Bradykinesia)

○0 ○1 ○2 ○3 ○4

0: Normal: No problems.

1: Slight: Slight global slowness and poverty of spontaneous movements.

2: Mild: Mild global slowness and poverty of spontaneous movements.

3: Moderate: Moderate global slowness and poverty of spontaneous movements.

4: Severe: Severe global slowness and poverty of spontaneous movements.

Tick once data is copied from this page to online

Visit date 20

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Case

Diagnosis <3y

Visit

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Tick here if completed directly online (you can leave the sheet blank)

3.15 Postural tremor of hands, 3.16 Kinetic tremor of hands, 3.17 Rest tremor amplitude

0: Normal: No tremor.

1: Slight: Tremor is present but less than 1 cm in amplitude.

2: Mild: Tremor is at least 1 but less than 3 cm in amplitude (for jaw rest tremor, less than 2cm).

3: Moderate: Tremor is at least 3 but less than 10 cm in amplitude (for jaw rest tremor, less than 3cm).

4: Severe: Tremor is at least 10 cm in amplitude (for jaw rest tremor, more than 3cm).

3.15 Postural tremor of hands

3.15a R hand ○0 ○1 ○2 ○3 ○4

3.15b L hand ○0 ○1 ○2 ○3 ○4

3.16 Kinetic tremor of hands

3.16a R hand ○0 ○1 ○2 ○3 ○4

3.16b L hand ○0 ○1 ○2 ○3 ○4

3.17 Rest tremor amplitude

3.17a Lip/jaw ○0 ○1 ○2 ○3 ○4

3.17b R arm ○0 ○1 ○2 ○3 ○4

3.17c L arm ○0 ○1 ○2 ○3 ○4

3.17d R leg ○0 ○1 ○2 ○3 ○4

3.17e L leg ○0 ○1 ○2 ○3 ○4

3.18 Constancy of Rest Tremor

○0 ○1 ○2 ○3 ○4

0: Normal: No tremor.

1: Slight: Tremor at rest is present < 25% of the entire examination period.

2: Mild: Tremor at rest is present 26 - 50% of the entire examination period.

3: Moderate: Tremor at rest is present 51 - 75% of the entire examination period.

4: Severe: Tremor at rest is present > 75% of the entire examination period.

Were dyskinesias present? ○No ○Yes

Did they interfere with ratings? ○No ○Yes

Patient's clinical state ○Off ○On

Tick once data is copied from this page to online

Visit date dd/mm/yyyy | **Centre** (2 digits) | **ID** (4 letters) | **Case** Diagnosis <3y | **Visit** V10 (72 months)

UPDRS Clinician Scoring

Hours awake

Hours with dyskinesia

Dyskinesia ratio

Use result for 4.1

Hours with dyskinesia divided by hours awake x 100

4.1 Time spent with dyskinesias

- 0: Normal: No dyskinesias.
- 1: Slight: < 25% of waking day.
- 2: Mild: 26 - 50% of waking day.
- 3: Moderate: 51 - 75% of waking day.
- 4: Severe: > 75% of waking day.

4.2 Functional impact of dyskinesias

- 0: Normal: No dyskinesias or no impact by dyskinesias on activities or social interactions.
- 1: Slight: Dyskinesias impact on a few activities, but the patient usually performs all activities and participates in all social interactions during dyskinetic periods.
- 2: Mild: Dyskinesias impact on many activities, but the patient usually performs all activities and participates in all social interactions during dyskinetic periods.
- 3: Moderate: Dyskinesias impact on activities to the point that the patient usually does not perform some activities or does not usually participate in some social activities during dyskinetic episodes.
- 4: Severe: Dyskinesias impact on function to the point that the patient usually does not perform most activities or participate in most social interactions during dyskinetic episodes.

Hours spent Off

Off ratio

Use result for 4.3

Hours spent Off divided by Hours awake x 100

4.3 Time spent in the off state

- 0: Normal: No OFF time.
- 1: Slight: < 25% of waking day.
- 2: Mild: 26 – 50% of waking day.
- 3: Moderate: 51 – 75% of waking day.
- 4: Severe: > 75% of waking day.

Tick once data is copied from this page to online

Tick here if completed directly online (you can leave the sheet blank)

4.4 Functional impact of fluctuations

0: Normal: No fluctuations or no impact by functuations on performance of activities or social interactions.

1: Slight: Fluctuations impact on a few activities but during OFF, the patient usually performs all activities and participates in all social interactions that typically occur during the ON state.

2: Mild: Fluctuations impact many activities, but during OFF, the patient still usually performs all activities and participates in all social interactions that typically occur during the ON state.

3: Moderate: Fluctuations impact on the performance of activities during OFF to the point that the patient usually does not perform some activities or participate in some social interactions that are performed during ON periods.

4: Severe: Fluctuations impact on function to the point that, during OFF, the patient usually does not perform most activities or participate in most social interactions that are performed during ON periods.

4.5 Complexity of motor fluctuations

0: Normal: No motor fluctuations.

1: Slight: OFF times are predictable all or almost all of the time (> 75%).

2: Mild: OFF times are predictable most of the time (51 - 75%).

3: Moderate: OFF times are predictable some of the time (26 - 50%).

4: Severe: OFF episodes are rarely predictable (< 25%).

Hours spent with dystonia

Hours spent with dystonia divided by OFF time x 100

Dystonia ratio

Use result for 4.6

4.6 Painful off-state dystonia

0: Normal: No dystonia, or no OFF time.

1: Slight: < 25% of time in OFF state.

2: Mild: 26 - 50% of time in OFF state.

3: Moderate: 51 - 75% of time in OFF state.

4: Severe: > 75% of time in OFF state.

Tick once data is copied from this page to online

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Tick here if completed directly online (you can leave the sheet blank) ○

Schwab and England

○ 100% - Completely independent. Able to do all chores without slowness, difficulty, or impairment. Essentially "normal". Unaware of difficulty.
○ 90% - Completely independent. Able to do all chores with some 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 slowing.
○ 70% - 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. Slower. Difficulty with everything.
○ 40% - Very dependent. Can assist with all chores but few alone.
○ 30% - With effort now and does a few chores alone or begins alone. Much help needed. Part invalid.
○ 20% - Nothing alone. Can be slight help with some chores. Severe invalid.
○ 10% - Totally dependent, helpless. Complete invalid.
○ 0% - Vegetative functions such as swallowing, bladder and bowel function are not functioning. Bedridden

Hoehn and Yahr stage

○ 0: No signs of disease.
○ 1: Unilateral symptoms only.
○ 1.5: Unilateral and axial involvement.
○ 2: Bilateral symptoms. No impairment of balance.
○ 2.5: Mild bilateral disease with recovery on pull test.
○ 3: Balance impairment. Mild to moderate disease. Physically independent.
○ 4: Severe disability, but still able to walk or stand unassisted.
○ 5: Needing a wheelchair or bedridden unless assisted.

Tick once data is copied from this page to online ○

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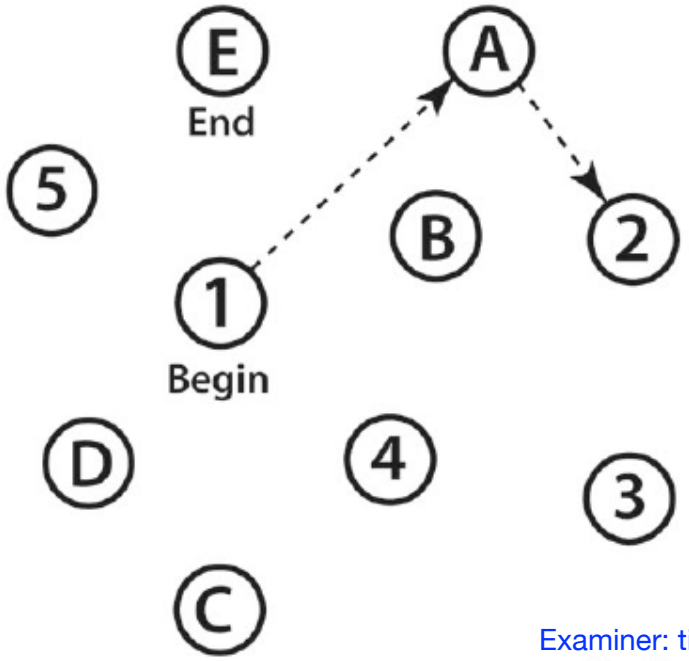
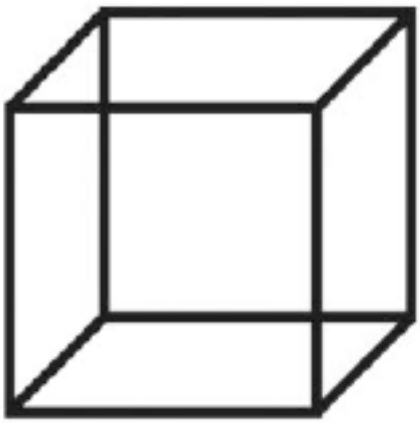
MoCA Montreal Cognitive Assessment (Incorporating MMSE)

1. Trail. Please draw a line, going from a number to a letter in ascending order. Begin at 1, and draw a line from 1 to A, then to 2 and so on. End at E



Examiner: tick if correct

2. Cube. Copy this drawing as accurately as you can, in the space below



Examiner: tick if correct

Tick once data is copied from this page to online

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4 letters

Case

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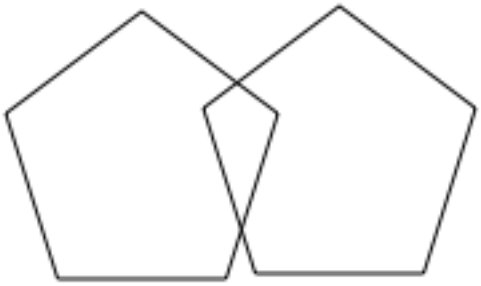
3a. Clock. Draw a clock. Put in all the numbers and set the time to 10 past 11

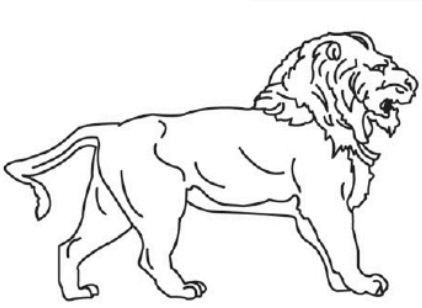
Examiner: tick if correctly done, for circle, numbers, hands

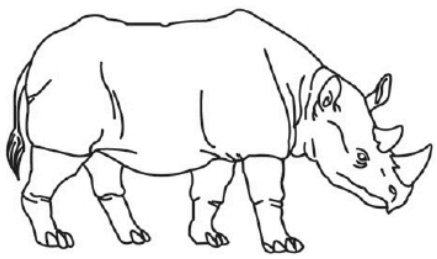
3b. Pentagons. Copy the interlocking pentagons

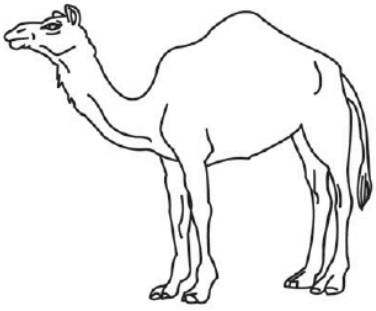


Examiner: tick if correct

4. Naming. Give the name of each animal







Examiner: tick if correct

Tick once data is copied from this page to online

5. Memory. "This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them."

(Read at 1 per second, examiner tick which are recalled)

	FACE	VELVET	CHURCH	DAISY	RED
1st TRIAL	☐	☐	☐	☐	☐

If necessary, repeat as follows: "I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time.

Examiner: do not record second trial

6. ATTENTION

Forward Digit Span:

Give the following instruction: *"I am going to say some numbers and when I am through, repeat them to me exactly as I said them".* Read the five number sequence at a rate of one digit per second.

Repeat 2, 1, 8, 5, 4 in forward order Examiner: tick if correct ☐

Backward Digit Span:

Give the following instruction: *"Now I am going to say some more numbers, but when I am through you must repeat them to me in the backwards order."* Read the three number sequence at a rate of one digit per second.

Repeat 7, 4, 2 in backward order Examiner: tick if correct ☐

Tick once data is copied from this page to online ☐

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Vigilance:

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

FBACMNAAJKLBAFAKDEAAAJAMOFAAB

Examiner: tick if correct

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

Serial 7's:

The examiner gives the following instruction: *"Now, I will ask you to count by subtracting seven from 100, and then, keep subtracting seven from your answer until I tell you to stop."* Give this instruction twice if necessary.

Serial 7's – ENTER THE NUMBER OF CORRECT ITEMS

○ 0 correct ○ 1 correct ○ 2 correct ○ 3 correct ○ 4 correct ○ 5 correct

Method: Count each correct subtraction of 7 beginning at 100.

Each subtraction is evaluated independently; that is, if the participant responds with an incorrect number but continues to correctly subtract 7 from it, give a point for each correct subtraction.

For example, a participant may respond "92-85-78-71-64" where the "92" is incorrect, but all the subsequent numbers are subtracted correctly.

This is one error and the item would be marked as **4 correct**.

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7. LANGUAGE. Sentence repetition:

I am going to read you a sentence. Repeat it after me, exactly as I say it [pause]: ***I only know that John is the one to help today."*** Following the response, say: *"Now I am going to read you another sentence. Repeat it after me, exactly as I say it* [pause]: ***The cat always hid under the couch when dogs were in the room.***

☐ I only know that John is the one to help today.
☐ The cat always hid under the couch when dogs were in the room.

Scoring: Allocate one point for each sentence correctly repeated. Repetition must be exact. Be alert for errors that are omissions (e.g. omitting "only", "always") and substitutions/additions (e.g. "John is the one who helped today;" substituting "hides" for "hid", altering plurals, etc).

8. LANGUAGE Fluency:

"Tell me as many words as you can think of that begin with a certain letter of the alphabet that I will tell you in a moment. You can say any kind of word you want, except for proper nouns (like Bob or Boston), numbers, or words that begin with the same sound but have a different suffix, for example, love, lover, loving. I will tell you to stop after one minute. Are you ready? [Pause] *Now, tell me as many words as you can think of that begin with the letter F.* [time for 60 sec]. *Stop."*

○ Manages 10 or less words beginning with F ○ Manages 11 or more

Scoring: Allocate one point if the subject generates 11 words or more in 60 sec.

Tick once data is copied from this page to online

9. ABSTRACTION

"Tell me how an orange and a banana are alike". If the subject answers in a concrete manner, then say only one additional time: *"Tell me another way in which those items are alike*". If the subject does not give the appropriate response *(fruit)*, say, *"Yes, and they are also both fruit."* Do not give any additional instructions or clarification. After the practice trial, say: *"Now, tell me how a train and a bicycle are alike*". Following the response, administer the second trial, saying: *"Now tell me how a ruler and a watch are alike"*. Do not give any additional instructions or prompts.

train-bicycle

○ 0 incorrect ○ 1 correct

watch-ruler

○ 0 incorrect ○ 1 correct

Scoring: Only the last two item pairs are scored. Give 1 point to each item pair correctly answered. The following responses are acceptable:
Train-bicycle = means of transportation, means of travelling, you take trips in both;
Ruler-watch = measuring instruments, used to measure.
The following responses are **not** acceptable: Train-bicycle = they have wheels; Ruler-watch = they have numbers.

10. DELAYED RECALL

"*I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember.*" Tick each of the words correctly recalled spontaneously without any cues, in the line following.

Select which words are recalled WITH NO CUE

☐ FACE ☐ VELVET ☐ CHURCH ☐ DAISY ☐ RED

Scoring: 1 point is allocated for each word recalled freely without any cues.

The system will count up based on the ticks you enter.

11. ORIENTATION

"Tell me the date today". If the subject does not give a complete answer, then prompt accordingly by saying: "*Tell me the [year, month, exact date, and day of the week].*" Then say: "*Now, tell me the name of this place, and which city it is in.*"

Date
○ Correct ○ Incorrect

Month
○ Correct ○ Incorrect

Year
○ Correct ○ Incorrect

Day
○ Correct ○ Incorrect

Place
○ Correct ○ Incorrect

City
○ Correct ○ Incorrect

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

The system will calculate the scores for you.

Tick once data is copied from this page to online ○

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2 digits

ID

4 letters

Case

Diagnosis <3y

Visit

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SEMANTIC FLUENCY

Tell me as many animals as you can. It doesn't matter what letter they start with. However, please try to avoid giving me lots of different breeds of the same animal or different versions of the same animal. Just try to think of as many *different* animals as you can. You will have 90 seconds before I tell you to stop. Do you have any questions? Ready? Begin?

[If no responses made for around 15 seconds, say Keep going. Prompt only once.]

ANIMALS Enter the person's responses here:

TOTAL CORRECT

Count the total number of correct answers given

Set-Loss errors

Count up words which are not correct as animals

Repetition Errors

Count up the answers which were repeated

Tick once data is copied from this page to online

Visit date

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dd/mm/yyyy

Centre

2 digits

ID

4 letters

Case

Diagnosis <3y

Visit

V10 (72 months)

Blood Tests

Tick here if completed directly online (you can leave the sheet blank)

Blood Samples

Use this section to notify of the collection and sending of a blood sample

You can also record here if a sample was due, and was not collected

Serum stored to freezer

- Yes
- No

If samples not processed per protocol, describe

- Not applicable
- Omitted in error at this visit (try to get next visit)
- Failed venepuncture
- Serum haemolysed
- Other (enter comment below)

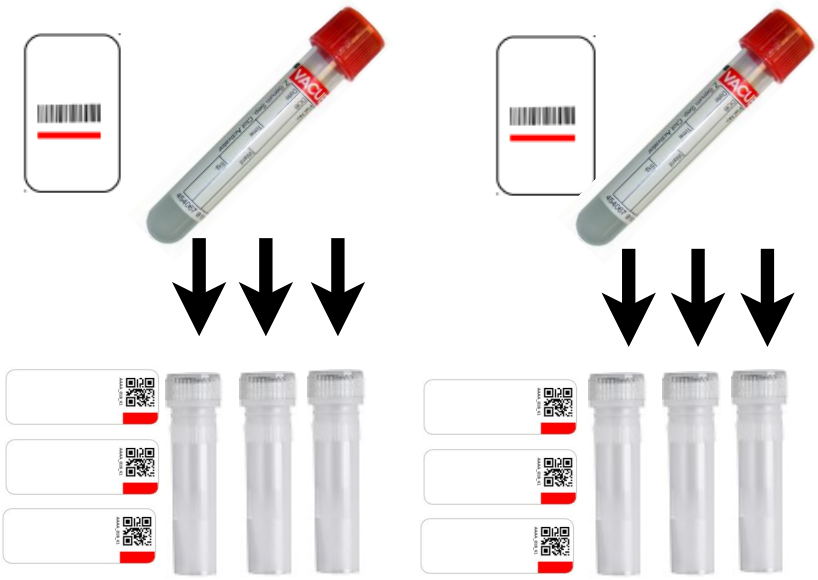
Describe Other reason, relating to blood sample

Blood sample for freezer

Stick a red barcode with the same ID and centre on to the SST tubes. Spin and pipette the serum into the 3 small freezer tubes and label with a QR code sticker. Do the same for the other SST tube and store the samples at -80 degrees

Barcode for SST tubes

This shows: ID Centre



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PDQ 8

(Parkinson's Disease Quality of Life 8-item version)

Due to having Parkinson's Disease, how often during the last month have you...

*(Please tick **one** box for each question)*

1. Had difficulty getting around in public?
Never Occasionally Sometimes Often Always or cannot do at all

2. Had difficulty dressing yourself?
Never Occasionally Sometimes Often Always or cannot do at all

3. Felt depressed?
Never Occasionally Sometimes Often Always or cannot do at all

4. Felt embarrassed in public due to having Parkinson's Disease?
Never Occasionally Sometimes Often Always or cannot do at all

5. Had problems with your close personal relationships?
Never Occasionally Sometimes Often Always or cannot do at all

6. Had problems with your concentration, e.g. when reading or watching TV?
Never Occasionally Sometimes Often Always or cannot do at all

7. Felt unable to communicate with people properly?
Never Occasionally Sometimes Often Always or cannot do at all

8. Had painful muscle cramps or spasms?
Never Occasionally Sometimes Often Always or cannot do at all

Please check that you have ticked one box for each question

please continue →

Tick once data is copied from this page to online

Visit date

20

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Centre

2 digits

ID

4 letters

Case

Diagnosis <3y

Visit

V10 (72 months)

EQ5D Quality of Life 5

Please complete the following questions

1. Mobility

- ◯ I have no problems in walking about
- ◯ I have some problems in walking about
- ◯ I am confined to bed

2. Self-Care

- ◯ I have no problems with self-care
- ◯ I have some problems washing or dressing myself
- ◯ I am unable to wash or dress myself

3. Usual Activities (e.g. work, study, housework, family or leisure activities)

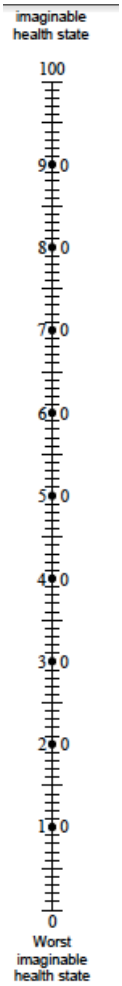
- ◯ I have no problems with performing my usual activities
- ◯ I have some problems with performing my usual activities
- ◯ I am unable to perform my usual activities

4. Pain/Discomfort

- ◯ I have no pain or discomfort
- ◯ I have moderate pain or discomfort
- ◯ I have extreme pain or discomfort

5. Anxiety/Depression

- ◯ I am not anxious or depressed
- ◯ I am moderately anxious or depressed
- ◯ I am extremely anxious or depressed



To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by selecting a number between 0 and 100 to indicate how good or bad your health state is today.

Tick once data is copied from this page to online ◯

please continue ⟶

ESS Epworth Sleep Scale

For each of the situations below please indicate how likely you are to doze off or fall asleep. This refers to your usual way of life in recent times. If your sleepiness is variable (for example, if you work shifts) then try and give an average. If you have not done some of these things, try and imagine how they would have affected you.

Tick ONLY ONE BOX for each situation corresponding to the probability of falling asleep in that situation.

1. Sitting and reading
◯ Never ◯ Slight chance ◯ Medium chance ◯ High chance

2. Watching TV
◯ Never ◯ Slight chance ◯ Medium chance ◯ High chance

3. Sitting inactive in a public place like a theatre or meeting
◯ Never ◯ Slight chance ◯ Medium chance ◯ High chance

4. As a passenger in a car for an hour without a break
◯ Never ◯ Slight chance ◯ Medium chance ◯ High chance

5. Lying down to rest in the afternoon when circumstances permit
◯ Never ◯ Slight chance ◯ Medium chance ◯ High chance

6. Sitting and talking to someone
◯ Never ◯ Slight chance ◯ Medium chance ◯ High chance

7. Sitting quietly after lunch without alcohol
◯ Never ◯ Slight chance ◯ Medium chance ◯ High chance

8. In a car, while stopped for a few minutes in traffic
◯ Never ◯ Slight chance ◯ Medium chance ◯ High chance

Tick once data is copied from this page to online ◯

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Visit

V10 (72 months)

RBD Screening Questionnaire

The following set of questions refers to your sleep and how restless you are in bed. For each of the sentences tick only one box depending on whether you agree (YES) or disagree (NO).

1. I sometimes have very vivid dreams.

Yes No

2. My dreams frequently have an aggressive or action-packed content.

Yes No

3. Dream contents mostly match my nocturnal behaviour.

Yes No

4. I know that my arms or legs move when I sleep.

Yes No

5. I have (or have almost) hurt my bed partner or myself by moving around while asleep.

Yes No

6. I have had the following during my dreams...

.... speaking, shouting, swearing, laughing loudly

Yes No

.... sudden limb movements, "fights"

Yes No

.... gestures, complex movements that are useless during sleep, e.g. waving, saluting, frightening mosquitoes, falling off the bed

Yes No

.... knocking things over e.g. bedside lamp, book, glasses

Yes No

7. My movements awake me.

Yes No

8. After wakening I mostly remember the content of my dreams well.

Yes No

9. My sleep is frequently disturbed.

Yes No

10. I have/had the following (tick any that apply to you)

- stroke
- head trauma
- parkinsonism
- restless legs syndrome
- narcolepsy
- depression
- epilepsy
- inflammatory disease of the brain
- other brain disease

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HADS Hospital Anxiety and Depression Scale

Read each item and tick the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or 'wound up':

☐ Most of the time ☐ A lot of the time ☐ From time to time, occasionally ☐ Not at all

2. I still enjoy the things I used to enjoy:

☐ Definitely as much ☐ Not quite so much ☐ Only a little ☐ Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:

☐ Very definitely and quite badly ☐ Yes, but not too badly ☐ A little, but it doesn't worry me ☐ Not at all

4. I can laugh and see the funny side of things:

☐ As much as I always could ☐ Not quite so much now ☐ Definitely not so much now ☐ Not at all

5. Worrying thoughts go through my mind:

☐ A great deal of the time ☐ A lot of the time ☐ From time to time, but not too often ☐ Only occasionally

6. I feel cheerful:

☐ Not at all ☐ Not often ☐ Sometimes ☐ Most of the time

7. I can sit at ease and feel relaxed:

☐ Definitely ☐ Usually ☐ Not often ☐ Not at all

8. I feel as if I am slowed down:

☐ Nearly all the time ☐ Very often ☐ Sometimes ☐ Not at all

9. I get a sort of frightened feeling like 'butterflies' in the stomach:

☐ Not at all ☐ Occasionally ☐ Quite often ☐ Very often

10. I have lost interest in my appearance:

☐ Definitely ☐ I don't take as much care as I should ☐ I may not take quite as much care ☐ I take just as much care as ever

11. I feel restless as I have to be on the move:

☐ Very much indeed ☐ Quite a lot ☐ Not very much ☐ Not at all

12. I look forward with enjoyment to things:

☐ As much as I ever did ☐ Rather less than I used to ☐ Definitely less than I used to ☐ Hardly at all

13. I get sudden feelings of panic:

☐ Very often indeed ☐ Quite often ☐ Not very often ☐ Not at all

14. I can enjoy a good book or radio or TV program:

☐ Often ☐ Sometimes ☐ Not often ☐ Very seldom

Tick once data is copied from this page to online

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QUIP

Answer all the questions based on behaviours ANYTIME SINCE YOUR PARKINSON'S DISEASE DIAGNOSIS LASTING AT LEAST 4 WEEKS. Tick ONLY ONE BOX for each point.

Gambling

1. Do (did) you or others think you have an issue with too much gambling behaviour (such as casinos, internet gambling, lotteries, scratch tickets, betting, or slot or poker machines)?

- ○ Yes
- ○ No

2. Do (did) you have difficulty controlling your gambling behaviour (such as increasing them over time, or having trouble cutting down or stopping them)?

- ○ Yes
- ○ No

Sex

1. Do (did) you or others think you have an issue with too much sex behaviours (such as making sexual demands on others, promiscuity, prostitution, change in sexual orientation, masturbation, internet or telephone sexual activities, or pornography)?

- ○ Yes
- ○ No

2. Do (did) you think too much about sex behaviours (such as having trouble keeping thoughts out of your mind or feeling guilty)?

- ○ Yes
- ○ No

Buying

1. Do (did) you or others think that you have an issue with too much buying behaviours (such as too much of the same thing or things that you don't need or use)?

- ○ Yes
- ○ No

2. Do (did) you engage in activities specifically to continue the buying behaviours (such as hiding what you're doing, lying, hoarding things, borrowing from others, accumulating debt, stealing, or being involved in illegal acts)?

- ○ Yes
- ○ No

Eating

1. Do (did) you or others think you have (had) an issue with too much eating behaviours (such as eating larger amounts or different types of food than in the past, more rapidly than normal, until feeling uncomfortably full, or when not hungry)?

- ○ Yes
- ○ No

2. Do (did) you have urges or desires for eating behaviours that you feel are (felt were) excessive or cause (caused) you distress (including becoming restless or irritable when unable to participate in the behaviour)?

- ○ Yes
- ○ No

Tick once data is copied from this page to online ○

please continue →

Other Behaviours

Do (did) you or others think that you spend (spent) too much time .....

1. On specific tasks, hobbies or other organised activities (such as writing, painting, gardening, repairing or dismantling things, collecting, computer use, working on projects etc)?

- ○ Yes
- ○ No

2. Repeating certain simple motor activities (such as cleaning, tidying, handling, examining, sorting, ordering or arranging objects etc)?

- ○ Yes
- ○ No

3. Walking or driving with no intended goal or purpose?

- ○ Yes
- ○ No

Medication use

1. Do (did) you or others (including your physicians) think that you consistently take (took) too much of your Parkinson's medications?

- ○ Yes
- ○ No

2. Do (did) you have difficulty controlling your use of Parkinson's medications (such as experiencing a strong desire for more medication, or having worse mood or feeling unmotivated at a lower dosage?)

- ○ Yes
- ○ No

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please continue →

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V10 (72 months)

Constipation Questionnaire

Please, answer the following questions by placing a tick in ONLY ONE BOX for each question.

1. In the past one week your average daily bowel movement frequency has been:

◯ <1 ◯ 1 ◯ 2 ◯ >2

2. In the past week have you used laxatives?

◯ Yes ◯ No

2.1 If YES, which one:

3. In the past one week your average daily consumption of fruit and vegetable has been:

◯ 1-3 portions ◯ 4-5 portions ◯ 6-8 portions ◯ >8 portions

4. Have you undertaken any exercise, e.g. jogging, in the past one week?

◯ Yes ◯ No

For each of the following symptoms please tick one answer for how you have felt over the past 2 weeks:

1. Nausea (feeling sick to your stomach as if you were going to vomit or throw up)

◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe

2. Retching (heaving as if to vomit, but nothing comes up)

◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe

3. Vomiting

◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe

4. Stomach fullness

◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe

5. Not able to finish a normal-sized meal

◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe

6. Feeling excessively full after meals

◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe

7. Loss of appetite

◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe

8. Bloating (feeling like you need to loosen your clothes)

◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe

9. Stomach or belly visibly larger

◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe

Tick once data is copied from this page to online ◯

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V10 (72 months)

SCOPA-AUT

By means of this questionnaire, we would like to find out to what extent in the past month you have had problems with various bodily functions, such as difficulty passing urine, or excessive sweating. Answer the questions by selecting which best reflects your situation. If you have used medication in the past month in relation to one or more of the problems mentioned, then the question refers to how you were while taking this medication.

1. In the past month have you had difficulty swallowing or have you choked?

☐ never ☐ sometimes ☐ regularly ☐ often

2. In the past month, has saliva dribbled out of your mouth?

☐ never ☐ sometimes ☐ regularly ☐ often

3. In the past month, has food ever become stuck in your throat?

☐ never ☐ sometimes ☐ regularly ☐ often

4. In the past month, did you ever have the feeling during a meal that you were full very quickly?

☐ never ☐ sometimes ☐ regularly ☐ often

5. *Constipation is a blockage of the bowel, a condition in which someone has a bowel movement twice a week or less.*

In the past month have you had problems with constipation?

☐ never ☐ sometimes ☐ regularly ☐ often

6. In the past month, did you have to strain hard to pass stools?

☐ never ☐ sometimes ☐ regularly ☐ often

7. In the past month, have you had involuntary loss of stools?

☐ never ☐ sometimes ☐ regularly ☐ often

Tick once data is copied from this page to online

please continue ⟶

Questions 8 to 13 deal with problems with passing urine. If you use a catheter you can indicate this by placing a cross in the box "*use catheter*".

8. In the past month, have you had difficulty retaining urine?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ Use catheter

9. In the past month, have you had involuntary loss of urine?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ Use catheter

10. In the past month, have you had the feeling that after passing urine your bladder was not completely empty?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ Use catheter

11. In the past month, has the stream of urine been weak?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ Use catheter

12. In the past month, have you had to pass urine again within 2 hours of the previous time?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ Use catheter

13. In the past month, have you had to pass urine at night?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ Use catheter

14. In the past month, when standing up have you had the feeling of either becoming light-headed, or no longer being able to see properly, or no longer being able to think clearly?
☐ never ☐ sometimes ☐ regularly ☐ often

15. In the past month, did you become light-headed after standing for some time?
☐ never ☐ sometimes ☐ regularly ☐ often

16. Have you fainted in the past 6 months?
☐ never ☐ sometimes ☐ regularly ☐ often

17. In the past month, have you ever perspired excessively during the day?
☐ never ☐ sometimes ☐ regularly ☐ often

18. In the past month, have you ever perspired excessively during the night?
☐ never ☐ sometimes ☐ regularly ☐ often

Tick once data is copied from this page to online ☐

please continue →

19. In the past month, have your eyes ever been over-sensitive to bright light?
☐ never ☐ sometimes ☐ regularly ☐ often

20. In the past month, how often have you had trouble tolerating cold?
☐ never ☐ sometimes ☐ regularly ☐ often

21. In the past month, how often have you had trouble tolerating heat?
☐ never ☐ sometimes ☐ regularly ☐ often

The following questions are about sexuality. Although we are aware that sexuality is a highly intimate subject, we would still like you to answer these questions. For the questions on sexual activity, consider every form of sexual contact with a partner or masturbation (self-gratification). An extra response option has been added to these questions. Here you can indicate that the situation described has not been applicable to you in the past month, for example because you have not been sexually active. Questions 22 and 23 are intended specifically for men, 24 and 25 for women.

The following 3 questions are only for men

22. In the past month, have you been impotent (unable to have or maintain an erection)?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ not applicable

23. In the past month, how often have you been unable to ejaculate?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ not applicable

23.a In the past month, have you taken medication for an erection disorder?
☐ Yes ☐ No

If so, which medication?

The following 2 questions are only for women

24. In the past month, was your vagina too dry during sexual activity?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ not applicable

25. In the past month, have you had difficulty reaching orgasm?
☐ never ☐ sometimes ☐ regularly ☐ often ☐ not applicable

Tick once data is copied from this page to online ☐

please continue →

UPDRS Patient-Completed Sections

1.7 Sleep Problems

- ◯ 0: Normal: No problems
- ◯ 1: Slight: Sleep problems are present but usually do not cause trouble getting a full night of sleep.
- ◯ 2: Mild: Sleep problems usually cause some difficulties getting a full night of sleep.
- ◯ 3: Moderate: Sleep problems cause a lot of difficulties getting a full night of sleep, but I still usually sleep for more than half the night.
- ◯ 4: Severe: I usually do not sleep for most of the night.

1.8 Daytime Sleepiness

- ◯ 0: Normal: No daytime sleepiness.
- ◯ 1: Slight: Daytime sleepiness occurs but I can resist and I stay awake.
- ◯ 2: Mild: Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV.
- ◯ 3: Moderate: I sometimes fall asleep when I should not. For example, while eating or talking with other people.
- ◯ 4: Severe: I often fall asleep when I should not. For example, while eating or talking with other people.

1.9 Pain and Other Sensations

- ◯ 0: Normal: No uncomfortable feelings.
- ◯ 1: Slight: I have these feelings. However, I can do things and be with other people without difficulty.
- ◯ 2: Mild: These feelings cause some problems when I do things or am with other people.
- ◯ 3: Moderate: These feelings cause a lot of problems, but they do not stop me from doing things or being with other people.
- ◯ 4: Severe: These feelings stop me from doing things or being with other people.

1.10 Urinary Problems

- ◯ 0: Normal: No urine control problems.
- ◯ 1: Slight: I need to urinate often or urgently. However, these problems do not cause difficulties with my daily activities.
- ◯ 2: Mild: Urine problems cause some difficulties with my daily activities. However, I do not have urine accidents.
- ◯ 3: Moderate: Urine problems cause a lot of difficulties with my daily activities, including urine accidents.
- ◯ 4: Severe: I cannot control my urine and use a protective garment or have a bladder tube.

Tick once data is copied from this page to online

please continue

1.11 Constipation Problems

0: Normal: No constipation.
1: Slight: I have been constipated. I use extra effort to move my bowels. However, this problem does not disturb my activities or my being comfortable.
2: Mild: Constipation causes me to have some troubles doing things or being comfortable.
3: Moderate: Constipation causes me to have a lot of trouble doing things or being comfortable. However, it does not stop me from doing anything.
4: Severe: I usually need physical help from someone else to empyt my bowels.

1.12 Light Headedness on Standing

0: Normal: No dizzy or foggy feelings.
1: Slight: Dizzy or foggy feelings occur. However, they do not cause me troubles doing things.
2: Mild: Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down.
3: Moderate: Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling.
4: Severe: Dizzy or foggy feelings cause me to fall or faint.

1.13 Fatigue

0: Normal: No fatigue.
1: Slight: Fatigue occurs. However it does not cause me troubles doing things or being with people.
2: Mild: Fatigue causes me some troubles doing things or being with people.
3: Moderate: Fatigue causes me a lot of troubles doing things or being with people. However, it does not stop me from doing anything.
4: Severe: Fatigue stops me from doing things or being with people.

2.1 Speech

0: Normal: Not at all (no problems).
1: Slight: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.
2: Mild: My speech causes people to ask me to occasionally repeat myself, but not everyday.
3: Moderate: My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood.
4: Severe: Most or all of my speech cannot be understood.

Tick once data is copied from this page to online

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2.2 Saliva & Drooling

- 0: Normal: Not at all (no problems).
- 1: Slight: I have too much saliva, but do not drool.
- 2: Mild: I have some drooling during sleep, but none when I am awake.
- 3: Moderate: I have some drooling when I am awake, but I usually do not need tissues or a handkerchief.
- 4: Severe: I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.

2.3 Chewing and Swallowing

- 0: Normal: No problems
- 1: Slight: I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared.
- 2: Mild: I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week.
- 3: Moderate: I choked at least once in the past week.
- 4: Severe: Because of chewing and swallowing problems, I need a feeding tube.

2.4 Eating Tasks

- 0: Normal: Not at all (No problems).
- 1: Slight: I am slow, but I do not need any help handling my food and have not had food spills while eating.
- 2: Mild: I am slow with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat.
- 3: Moderate: I need help with many eating tasks but can manage some alone.
- 4: Severe: I need help for most or all eating tasks.

2.5 Dressing

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow but I do not need help.
- 2: Mild: I am slow and need help for a few dressing tasks (buttons, bracelets).
- 3: Moderate: I need help for many dressing tasks.
- 4: Severe: I need help for most or all dressing tasks.

2.6 Hygiene

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow but I do not need any help.
- 2: Mild: I need someone else to help me with some hygiene tasks.
- 3: Moderate: I need help for many hygiene tasks.
- 4: Severe: I need help for most or all of my hygiene tasks.

Tick once data is copied from this page to online

please continue

2.7 Handwriting

- 0: Normal: Not at all (no problems).
- 1: Slight: My writing is slow, clumsy or uneven, but all words are clear.
- 2: Mild: Some words are unclear and difficult to read.
- 3: Moderate: Many words are unclear and difficult to read.
- 4: Severe: Most or all words cannot be read.

2. 8 Doing Hobbies and Other Activities

- 0: Normal: Not at all (no problems).
- 1: Slight: I am a bit slow but do these activities easily.
- 2: Mild: I have some difficulty doing these activities.
- 3: Moderate: I have major problems doing these activities, but still do most.
- 4: Severe: I am unable to do most or all of these activities.

2.9 Turning in Bed

- 0: Normal: Not at all (no problems).
- 1: Slight: I have a bit of trouble turning, but I do not need any help.
- 2: Mild: I have a lot of trouble turning and need occasional help from someone else.
- 3: Moderate: To turn over I often need help from someone else.
- 4: Severe: I am unable to turn over without help from someone else.

2.10 Tremor

- 0: Normal: Not at all. I have no shaking or tremor.
- 1: Slight: Shaking or tremor occurs but does not cause problems with any activities.
- 2: Mild: Shaking or tremor causes problems with only a few activities.
- 3: Moderate: Shaking or tremor causes problems with many of my daily activities.
- 4: Severe: Shaking or tremor causes problems with most or all activities.

2.11 Getting out of bed, a car, or a deep chair

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow or awkward, but I usually can do it on my first try.
- 2: Mild: I need more than one try to get up or need occasional help.
- 3: Moderate: I sometimes need help to get up, but most times I can still do it on my own.
- 4: Severe: I need help most or all of the time.

Tick once data is copied from this page to online

please continue

2.12 Walking and Balance

0: Normal: Not at all (no problems).
1: Slight: I am slightly slow or may drag a leg. I never use a walking aid.
2: Mild: I occasionally use a walking aid, but I do not need any help from another person.
3: Moderate: I usually use a walking aid (cane, walker) to walk safely without falling. However, I do not usually need the support of another person.
4: Severe: I usually use the support or another person to walk safely without falling.

2.13 Freezing

0: Normal: Not at all (no problems).
1: Slight: I briefly freeze but I can easily start walking again. I do not need help from someone else or a walking aid (cane or walker) because of freezing.
2: Mild: I freeze and have trouble starting to walk again, but I do not need someone's help or a walking aid (cane or walker) because of freezing.
3: Moderate: When I freeze I have a lot of trouble starting to walk again and, because of freezing, I sometimes need to use a walking aid or need someone else's help.
4: Severe: Because of freezing, most or all of the time, I need to use a walking aid or someone's help.

NMSS Non-Motor Symptom Scale

1. Do you experience light-headedness, dizziness or weakness on standing from a sitting or lying position?

Severity
- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency
- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

2. Do you fall because of fainting or blacking out?

Severity
- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency
- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

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

Severity
- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency
- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

Tick once data is copied from this page to online ○

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4. Does fatigue (tiredness) or lack of energy (not slowness) limit your daytime activities?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

5. Do you have difficulty falling or staying asleep?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

6. Do you experience an urge to move the legs or restlessness in your legs (that improves with movement) when you are sitting or lying down inactive?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

Tick once data is copied from this page to online ○

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7. Have you lost interest in your surroundings?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

8. **Have you lost interest in doing things or lack motivation to start new activities?**

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

9. **Do you feel nervous, worried or frightened for no apparent reason?**

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

Tick once data is copied from this page to online ○

please continue →

10. Do you seem sad or depressed or have you reported such feelings?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

11. Do you have flat moods without the normal "highs" and "lows"?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

12. Do you have difficulty in experiencing pleasure from your usual activities or report that they lack pleasure?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

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13. Do you see things that are not there?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

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

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

15. Do you experience double vision? (Two separate real objects are not blurred vision)

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

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			V10 (72 months)

16. Do you have problems sustaining concentration during activities? (For example, reading or having a conversation)

Severity
- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency
- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

17. Do you forget things that you have been told a short time ago or events that happened in the last few days?

Severity
- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency
- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

18. Do you forget to do things? (For example, take tablets or turn off domestic appliances?)

Severity
- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency
- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

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19. Do you dribble saliva during the day?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

20. Do you have difficulty swallowing?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

21. Do you suffer from constipation? (Bowel action less than 3 times per week)

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

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22. Do you have difficulty holding urine? (Urgency)

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

23. Do you have to pass urine within two hours of last passing urine? (Frequency)

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

24. Do you have to get up regularly at night to pass urine?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

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25. Do you have an altered interest in sex?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

26. Do you have problems having sex?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

27. Do you suffer from pain not explained by other known conditions? (This mean pain relieved by anti-Parkinson drugs)

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

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28. Do you have a change in ability to taste or smell?

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

29. Have you had a recent change in weight? (Not related to dieting)

For all questions on this page, if Severity is answered "no," please leave Frequency unmarked.

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

30. Do you experience excessive sweating? (Not related to hot weather)

Severity

- ○ No
- ○ Mildly: Symptoms present but cause little distress or disturbance
- ○ Moderately: Some distress or disturbance
- ○ Severely: Major source or distress or disturbance

Frequency

- ○ Rarely (less than once per week)
- ○ Often (once per week)
- ○ Frequently (several times per week)
- ○ Very frequently (daily or all the time)

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PDSS PD Sleep Score

How would you rate the following, based on your experience during the past one week. (Place a cross at the appropriate point on the line)

1.	The overall quality of your night's sleep is:	AWFUL — EXCELLENT
2.	Do you have difficulty falling asleep each night?	ALWAYS — NEVER
3.	Do you have difficulty staying asleep?	ALWAYS — NEVER
4.	Do you have restlessness of legs or arms at night or in the evening causing disruption of sleep?	ALWAYS — NEVER
5.	Do you fidget in bed?	ALWAYS — NEVER
6.	Do you suffer from distressing dreams at night?	ALWAYS — NEVER
7.	Do you suffer from distressing hallucination at night (seeing or hearing things that you are told do not exist)?	ALWAYS — NEVER
8.	Do you get up at night to pass urine?	ALWAYS — NEVER
9.	Do you have incontinence of urine because you are unable to move due to "off" symptoms?	ALWAYS — NEVER
10.	Do you experience numbness or tingling of your arms or legs which wake you from sleep at night?	ALWAYS — NEVER
11.	Do you have painful muscle cramps in your arms or legs whilst sleeping at night?	ALWAYS — NEVER
12.	Do you wake early in the morning with painful posturing of arms or legs?	ALWAYS — NEVER
13.	On waking do you experience tremor?	ALWAYS — NEVER
14.	Do you feel tired and sleepy after waking in the morning?	ALWAYS — NEVER
15.	Have you unexpectedly fallen asleep during the day?	FREQUENTLY — NEVER

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ID

4 letters

Case

Diagnosis <3y

Visit

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Wearing Off Questionnaire

Please complete Yes or No for the following questions

I have experienced these symptoms in the past month, on an average day		Usually improves after my next dose of Parkinson's medication	
1. Tremor (e.g. shaking of hands, arms or legs)	○Yes ○No	If Yes...	○Yes ○No
2. Any slowness of movement (e.g. walking, eating, or dressing)	○Yes ○No	If Yes...	○Yes ○No
3. Mood changes	○Yes ○No	If Yes...	○Yes ○No
4. Any stiffness (e.g. rigidity of arms or legs)	○Yes ○No	If Yes...	○Yes ○No
5. Pain / aching	○Yes ○No	If Yes...	○Yes ○No
6. Reduced dexterity (e.g. difficulty buttoning or writing)	○Yes ○No	If Yes...	○Yes ○No
7. Cloudy mind / slowness of thinking	○Yes ○No	If Yes...	○Yes ○No
8. Anxiety / panic attacks	○Yes ○No	If Yes...	○Yes ○No
9. Muscle cramping (e.g. arms, legs, or feet)	○Yes ○No	If Yes...	○Yes ○No

Thank you. The questions for this visit are now complete.

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