

The Fresco Institute for Parkinson's and Movement Disorders

Follow Up Patient Questionnaire

Name: _____ Date: _____

Accompanied by: _____ Do you smoke? CURRENT PAST NEVER

Which neurological symptom bothers you most right now? _____

Any new medical problems, hospitalizations, surgeries, or allergies (since your last visit)? Y N

If yes, then please explain: _____

Medications for Parkinsonism and related symptoms (or attach your own list):

Medication Name	Dose:	Time:	Time:	Time:	Time:	Time:	Time:	Time:	Time:
Sinemet (carbidopa/levodopa)									
Sinemet CR (carbidopa/levodopa ER)									
Parcopa (carbidopa/levodopa dissolving)									
Stalevo (carbidopa/levodopa/entacapone)									
Selegiline	5 mg								
Azilect (rasagiline)									
Mirapex (pramipexole)									
Mirapex ER (pramipexole ER)									
Requip (ropinirole)									
Requip XL (ropinirole XL)									
Neupro (rotigotine patch)									
Comtan (entacapone)	200 mg								
Symmetrel (amantadine)	100 mg								

Other Medications, Vitamins, & Supplements (or attach your own list):

Medication Name	Dose (or # of mg)	Time:	Time:	Time:	Time:	Time:	Time:

Do you (or others) think that you spend (or waste) too much time on any of the following?

- | | | | | | |
|--|---|---|--|---|---|
| Shopping (in stores or on the internet) _____ | Y | N | Gambling (including scratch offs) _____ | Y | N |
| Sorting, cleaning, organizing, or tidying up _____ | Y | N | Having sexual thoughts or behaviors _____ | Y | N |
| Eating (or craving foods) _____ | Y | N | On the internet or playing video games _____ | Y | N |
| Pursuing your hobbies _____ | Y | N | Pursuing other specific activities _____ | Y | N |

Date: _____

The Fresco Institute for Parkinson's and Movement Disorders

Activities of Daily Living Questionnaire

Choose the statement that best describes how you have been feeling, since your last visit, **because of your neurological problems.**

Please circle only **ONE ANSWER.**

1. **Do you ever have forgetfulness or loss of memory (e.g., difficulty remembering names, telephone numbers)?**

- 0 No. I do not have forgetfulness or loss of memory.
- 1 Yes. I have mild and consistent forgetfulness.
- 2 Yes. I have moderate memory loss. Sometimes I am disoriented and have difficulty handling complex problems.
- 3 Yes. I have severe memory loss. At times, I am not sure where I am or what day or time it is.
- 4 Yes. I have severe memory loss. I usually don't know where I am or what day or time it is. I can't be left alone.

2. **Do you have hallucinations? (A hallucination is when you see or hear something that is not really there).**

- 0 No. I do not have hallucinations.
- 1 No. I do not have hallucinations, but at night I frequently have vivid nightmares.
- 2 Yes. I have hallucinations, but when I have them, I realize that what is happening is not real and is only imaginary.
- 3 Yes. I have frequent hallucinations that interfere with my ability to function on a day-to-day basis.
- 4 Yes. I have so many hallucinations that I am unable to take care of myself.

3. Do you experience depression (e.g., feelings of sadness and hopelessness, tearfulness, poor appetite)?

- 0 No. I do not experience depression.
- 1 Yes. I have periods of sadness that are greater than normal, but I am never depressed for more than one week.
- 2 Yes. I have periods of sadness that are greater than normal; I am sometimes depressed for more than one week.
- 3 Yes. I have periods of depression where I have difficulty sleeping, loss of appetite or loss of interest in things. These periods last longer than one week.
- 4 Yes. I have constant depression with difficulty sleeping, loss of appetite or loss of interest. Sometimes I even have suicidal thoughts.

4. Do you have loss of motivation or interest?

- 0 No. I do not have loss of motivation or interest. I am not more passive than I used to be.
- 1 Yes. I am more passive than I used to be.
- 2 Yes. I have loss of interest in activities like going out or socializing with friends.
- 3 Yes. I have lost interest in even day-to-day activities like getting bathed, getting dressed and going to work.
- 4 Yes. I am withdrawn and have complete loss of interest in anything.

5. Have you noticed that your speech has changed or do you have problems speaking?

- 0 No. My speech has not changed.
- 1 Yes. My speech is mildly affected but I have no difficulty being understood.
- 2 Yes. My speech is mildly affected and I am sometimes asked to repeat myself.
- 3 Yes. My speech is severely affected and I am sometimes asked to repeat myself.
- 4 Yes. My speech is so severely affected that it is hard for others to understand me.

6. Have you noticed that you have too much saliva?

- 0 No. I do not have too much saliva and I never drool.
- 1 Yes. I have a slight excess of saliva. Sometimes I drool into my pillow at night.
- 2 Yes. I have moderately excessive saliva and I occasionally drool during the daytime.
- 3 Yes. I have markedly excessive saliva and I often drool during the daytime.
- 4 Yes. I have been drooling so much that I often carry a tissue or handkerchief.

7. Do you have problems swallowing or do you choke on your food?

- 0 No. I do not have problems swallowing and I do not choke.
- 1 Yes. I have problems with swallowing but I rarely choke.
- 2 Yes. I have problems with swallowing and I occasionally choke.
- 3 Yes. I have problems with swallowing and I have to eat soft food.
- 4 Yes. I am unable to swallow and must use an NG or gastrostomy tube to eat

8. Have you noticed a change in your handwriting?

- 0 No. I do not notice a change in my handwriting.
- 1 Yes. My handwriting is slightly slow or small.
- 2 Yes. My handwriting is moderately slow or small but all of the words are readable.
- 3 Yes. My handwriting is severely affected. Not all of the words are readable.
- 4 Yes. My handwriting is severely affected. Most of the words are readable.

9. Do you have slowness or difficulties using utensils or cutting your food?

- 0 No. I do not have slowness or difficulty cutting my food.
- 1 Yes. I am a little slow or clumsy, but I am able to feed myself without help.
- 2 Yes. I am slow or clumsy. I need help cutting some types of food.
- 3 Yes. Someone must cut my food, but I am still able to feed myself.
- 4 Yes. I am unable to feed myself. Someone else feeds me.

10. Do you have difficulties with dressing?

- 0 No. I do not have slowness or difficulty with dressing.
- 1 Yes. I am a little slow or clumsy, but I don't need any help.
- 2 Yes. I am slow and sometimes need help buttoning buttons, tying shoelaces or getting my arm into a sleeve.
- 3 Yes. I need a lot of help getting dressed but I can still do some things on my own.
- 4 Yes. I am unable to get dressed without assistance.

11. Have you slowed down or are you experiencing problems with bathing, brushing your teeth, combing your hair, or going to the bathroom?

- 0 No. I am not slow with these activities.
- 1 Yes. I am a little slow with these activities but I do not need help.
- 2 Yes. I am slow with these activities and I need help to shower/bathe.
- 3 Yes. I need help with washing, brushing my teeth, combing my hair and going to the bathroom.
- 4 Yes. I need help with all these activities and I have a Foley Catheter.

12. Do you have difficulty turning in bed or adjusting the sheets?

- 0 No. I do not have difficulties turning in bed or adjusting my sheets.
- 1 Yes. I am a little clumsy or slow with turning in bed and adjusting the sheets but I do not need any help.
- 2 Yes. I am only able to turn or adjust the sheets with great difficulty.
- 3 Yes. I am able to start turning but am unable to do it without help.
- 4 Yes. I am not able to turn in bed or adjust the sheets without help.

13. Do you have problems with falling?

- 0 No. I do not fall.
- 1 Yes. I rarely fall.
- 2 Yes. I occasionally fall but less than once per day.
- 3 Yes. I fall an average of once per day.
- 4 Yes. I fall an average of more than once per day.

14. Do you have freezing while you are walking? (Freezing is when you are unable to walk for a few seconds because your feet 'stutter' or seem stuck to the ground)

- 0 No. I do not have freezing.
- 1 Yes. I have been freezing when I walk but this rarely happens **OR**
Yes. Sometimes when I first start to walk I have been freezing.
- 2 Yes. I occasionally have freezing when I walk.
- 3 Yes. I frequently have freezing when I walk. I occasionally fall because of the freezing.
- 4 Yes. I frequently have freezing when I walk. I frequently fall because of the freezing.

15. Has your walking changed? Is it difficult to walk?

- 0 No. My walking and my arm swing have not changed.
- 1 Yes. I do not swing my arms and I tend to drag my legs.
- 2 Yes. I have a moderate amount of difficulty with walking but usually don't need assistance.
- 3 Yes. I have severe problems with walking and usually need assistance.
- 4 Yes. I can't walk at all, even when someone tries to help me.

16. Do you have visible tremor anywhere in your body?

- 0 No. I do not have a visible tremor.
- 1 Yes. I have a slight visible tremor, which is infrequently present.
- 2 Yes. I have a moderate amount of tremor. The tremor bothers me.
- 3 Yes. I have a severe amount of tremor and it interferes with many activities.
- 4 Yes. I have a severe tremor and it interferes with most activities.

17. Do you have numbness, tingling, discomfort or aching that you would attribute to your Parkinson's disease (or other movement disorder)?

- 0 No. I do not have numbness, tingling, discomfort or aching that I attribute to my Parkinson's disease (or other movement disorder).
- 1 Yes. I do have occasional numbness, tingling, discomfort or aching that I attribute to my Parkinson's disease (or other movement disorder).
- 2 Yes. I frequently have numbness, tingling or aching that I attribute to my Parkinson's disease (or other movement disorder).
- 3 Yes. I frequently have painful sensations that I attribute to my Parkinson's disease (or other movement disorder).
- 4 Yes. I have excruciating pain that I attribute to my Parkinson's disease (or other movement disorder).

In the following table, please circle the number that fits you best.

How well do you perform chores and other daily activities such as preparing food, eating, dressing, washing, and using the toilet?

- 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. May take three to four times as long. 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 are made, and some chores are impossible.
- 50%** = More dependent. Help needed with half of chores. Slower. Difficulty with everything.
- 40%** = Very dependent. Able to assist with chores, but can do few alone.
- 30%** = With effort, can occasionally do a few chores alone, or at least begin them alone. Much help is needed.
- 20%** = Can't do any chores alone. Can be a slight help with some chores. Severe invalid.
- 10%** = Totally dependent, helpless. Complete invalid.
- 0%** = Bedridden, with loss of control of swallowing, bowels, and/or bladder function.

PD NMS QUESTIONNAIRE

Name:

Date:

Age:

Centre ID:

Male

Female

NON-MOVEMENT PROBLEMS IN PARKINSON'S

The movement symptoms of Parkinson's are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the doctor knows about these, particularly if they are troublesome for you.

A range of problems is listed below. Please tick the box 'Yes' if you have experienced it **during the past month**. The doctor or nurse may ask you some questions to help decide. If you have **not** experienced the problem in the past month tick the 'No' box. You should answer 'No' even if you have had the problem in the past but not in the past month.

Have you experienced any of the following in the last month?

- | | Yes | No | | Yes | No |
|---|--------------------------|--------------------------|--|--------------------------|--------------------------|
| 1. Dribbling of saliva during the daytime | <input type="checkbox"/> | <input type="checkbox"/> | 16. Feeling sad, 'low' or 'blue' | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Loss or change in your ability to taste or smell | <input type="checkbox"/> | <input type="checkbox"/> | 17. Feeling anxious, frightened or panicky | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Difficulty swallowing food or drink or problems with choking | <input type="checkbox"/> | <input type="checkbox"/> | 18. Feeling less interested in sex or more interested in sex | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Vomiting or feelings of sickness (nausea) | <input type="checkbox"/> | <input type="checkbox"/> | 19. Finding it difficult to have sex when you try | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Constipation (less than 3 bowel movements a week) or having to strain to pass a stool (faeces) | <input type="checkbox"/> | <input type="checkbox"/> | 20. Feeling light headed, dizzy or weak standing from sitting or lying | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Bowel (fecal) incontinence | <input type="checkbox"/> | <input type="checkbox"/> | 21. Falling | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Feeling that your bowel emptying is incomplete after having been to the toilet | <input type="checkbox"/> | <input type="checkbox"/> | 22. Finding it difficult to stay awake during activities such as working, driving or eating | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. A sense of urgency to pass urine makes you rush to the toilet | <input type="checkbox"/> | <input type="checkbox"/> | 23. Difficulty getting to sleep at night or staying asleep at night | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Getting up regularly at night to pass urine | <input type="checkbox"/> | <input type="checkbox"/> | 24. Intense, vivid dreams or frightening dreams | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Unexplained pains (not due to known conditions such as arthritis) | <input type="checkbox"/> | <input type="checkbox"/> | 25. Talking or moving about in your sleep as if you are 'acting' out a dream | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Unexplained change in weight (not due to change in diet) | <input type="checkbox"/> | <input type="checkbox"/> | 26. Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Problems remembering things that have happened recently or forgetting to do things | <input type="checkbox"/> | <input type="checkbox"/> | 27. Swelling of your legs | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Loss of interest in what is happening around you or doing things | <input type="checkbox"/> | <input type="checkbox"/> | 28. Excessive sweating | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Seeing or hearing things that you know or are told are not there | <input type="checkbox"/> | <input type="checkbox"/> | 29. Double vision | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Difficulty concentrating or staying focussed | <input type="checkbox"/> | <input type="checkbox"/> | 30. Believing things are happening to you that other people say are not true | <input type="checkbox"/> | <input type="checkbox"/> |

All the information you supply through this form will be treated with confidence and will only be used for the purpose for which it has been collected. Information supplied will be used for monitoring purposes. Your personal data will be processed and held in accordance with the Data Protection Act 1998.

Developed and validated by the International PD Non Motor Group
For information contact: susanne.tluk@uhl.nhs.uk or alison.forbes@uhl.nhs.uk