

International Parkinson and Movement Disorder Society

Non-Motor Fluctuation Assessment Questionnaire

Authored by: Galit Kleiner, MD Hubert H Fernandez MD Kelvin L Chou MD Alfonso A Fasano MD PhD Kevin R Duque MD **Diana Hengartner MD** Albie Law BA, CCRA Adam Margolius MD Yu-Yan Poon RN Michel Sáenz-Farret MD Philip Saleh MD MSc Joaquin Vizcarra MD Glenn T Stebbins PhD Alberto J Espay MD MSc on behalf of the PSG NoMoFA Working Group

Tel +1 (414) 276-2145 **Fax** +1 (414) 276-3349

555 E. Wells Street, Suite 1100 Milwaukee, WI 53202-3823 www.movementdisorders.org ratingscales@movementdisorders.org

Copyright © 2021 International Parkinson and Movement Disorder Society. All rights reserved.

MDS Permissions

The NoMoFA is owned and licensed by the International Parkinson and Movement Disorder Society (MDS). Permission is required to use the scale and can be obtained by submitting a <u>Permissions Request Form</u> on the MDS website. For licensing inquiries, please e-mail <u>ratingscales@movementdisorders.org</u>.

Unauthorized reproduction, distribution, translation, or sale of any portion of the NoMoFA is strictly prohibited. Changes, modifications and derivative works of the scale are not permitted without the express authorization of MDS. Including but not limited to the following, the NoMoFA may not be incorporated into clinical trials, training materials, certification programs, software programs, electronic platforms, electronic medical records, databases, or devices except by permission of MDS.

Non-Motor Fluctuation Assessment (NoMoFA) Questionnaire

Name:			
Who filled out this questionnaire:	□ Person with Parkinson's □ Care-partner □ Person with Parkinson's and Care-partner		
Date completed://			

Many people with Parkinson's disease have symptoms related to their movement (**motor symptoms**).

These may include, but are not limited to:

- stiffness
- slowness in carrying out movements
- trouble with walking
- tremors
- getting up from a chair
- using their hands

However, people with Parkinson's disease can also have symptoms that are not related to their movement (**non-motor symptoms**).

These non-motor symptoms may include, but are not limited to:

- problems in thinking and memory
- pain
- abnormal body sensations
- difficulty with emptying bowels
- trouble with the bladder

Many people do not know that these **non-motor symptoms** may be either caused by Parkinson's disease or as a side-effect of Parkinson's disease medications.

Some people living with Parkinson's disease have a good effect from their medications that reduce their symptoms; we call that **"ON"** time.

Sometimes, even when taking medications, there is poor control of symptoms; we call these low periods "**OFF**" time.

For people experiencing **non-motor symptoms**, taking medications like levodopa, also known as I-dopa, may make their **non-motor symptoms** better or worse. In some cases the **non-motor symptoms** are there all the time and don't get better or worse with I-dopa medications.

INSTRUCTIONS:

You will be asked to answer a series of questions related to <u>your</u> non-motor symptoms.

For each non-motor symptom, you will be asked three things over the past **two** weeks:

- 1. Whether you have the **non-motor symptom**
- 2. If the non-motor symptom was present, rate how bothersome it was for you on average. The choices of answers are: mild, moderate, or severe, as per the following definitions:
 - **Mild:** The problem did not affect my ability to carry out normal daily tasks or social activities
 - **Moderate:** The problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - Severe: The problem prevented me from carrying out normal daily tasks or social activities
- 3. If the non-motor symptom was:
 - worse during ON time (when I-dopa was working to control symptoms) or,
 - worse during OFF time (when I-dopa was not working) or,
 - no difference, meaning you experienced the same severity of the nonmotor symptom during ON or OFF time

- 1. In the last 2 weeks, did you lose your train of thought?
 - **YES INO** If NO, please proceed to Question 2.
 - A. If **yes**, on average how **severe** was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

	DFF 🗆 N	O DIFFERENCE
--	---------	--------------

2. In the last 2 weeks, did you get distracted from completing a task?

			If NO, please proceed to Question 3.
A. I	lf yes , on average h	ow severe w	vas this problem?

- **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
- **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
- **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

3. In the last 2 weeks, did you have **difficulty planning or carrying out an activity**? (For example, planning a party or making a grocery list, etc.)

- **YES INO** If NO, please proceed to Question 4.
- A. If **yes**, on average how **severe** was this problem?
 - **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

		NO DIFFERENCE
--	--	---------------

4. In the last 2 weeks, were you **confused such that you had difficulty performing simple tasks**?

(For example, preparing a cup of tea, making a phone call)

- **YES INO** If NO, please proceed to Question 5.
- A. If yes, on average how severe was this problem?
 - MILD the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>**ON**</u> (levodopa was working), or <u>**OFF**</u> (levodopa was not working)?

5. In the last 2 weeks, did you have difficulty finding the right words when speaking?

YES I NO If NO, please proceed to Question 6.

A. If **yes**, on average how **severe** was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

6. In the last 2 weeks, were you excessively worried?

YES		If NO, please proceed to Question 7.
-----	--	--------------------------------------

- A. If **yes**, on average how **severe** was this problem?
 - **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

7. In the last 2 weeks, did you feel scared or threatened?

YES I NO If NO, please proceed to Question 8.

A. If **yes**, on average how **severe** was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

8. In the last 2 weeks, did you feel restless?

YES		If NO, please proceed to Question 9.
-----	--	--------------------------------------

- A. If yes, on average how severe was this problem?
 - **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>**ON**</u> (levodopa was working), or <u>**OFF**</u> (levodopa was not working)?

9. In the last 2 weeks, did you feel hopeless or excessively sad?

YES INO If NO, please proceed to Question 10.

A. If **yes**, on average how **severe** was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

10. In the last 2 weeks, were you more likely to feel lonely or isolated?

YES INO If NO, please proceed to Question	1 <i>1</i> 1 1.
--	-----------------

A. If yes, on average how severe was this problem?

- **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
- **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
- **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

11. In the last 2 weeks, did you see things or people that were not there?

YES INO If NO, please proceed to Question 12.

A. If **yes**, on average how **severe** was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

12. In the last 2 weeks, did you make poor decisions?

\Box YES \Box NO If NO, ple	lease proceed to Question 13.
---------------------------------	-------------------------------

- A. If yes, on average how severe was this problem?
 - **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

13. In the last 2 weeks, were you more likely to **act quickly without thinking things through**?

YES INO If NO, please proceed to Question 14.

A. If yes, on average how severe was this problem?

- **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
- **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
- **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

14. In the last 2 weeks, were you more likely to have a strong uncontrollable urge to do things?

(For example, excessive gambling, eating too much, spending too much money or having more frequent thoughts about sexual activity)

YES INO If NO, please proceed to Question 15.

A. If yes, on average how severe was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>**ON**</u> (levodopa was working), or <u>**OFF**</u> (levodopa was not working)?

15. In the last 2 weeks, did you **have poor short-term memory**? (For example, putting things down and forgetting where you put them)

- **YES INO** If NO, please proceed to Question 16.
- A. If yes, on average how severe was this problem?
 - MILD the problem did not affect my ability to carry out normal daily tasks or social activities
 MODERATE the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 SEVERE the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

16. In the last 2 weeks, did you **have difficulty handling stressful situations** or felt overwhelmed in stressful situations?

- **YES INO** If NO, please proceed to Question 17.
- A. If yes, on average how severe was this problem?
 - MILD the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were **ON** (levodopa was working), or **OFF** (levodopa was not working)?

17. In the last 2 weeks, did you **lose interest in activities that you previously enjoyed**?

- **YES INO** If NO, please proceed to Question 18.
- A. If yes, on average how severe was this problem?
 - **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

18. In the last 2 weeks, did you feel sluggish or had low energy levels?

	If NO, please proceed to Question 19.
--	---------------------------------------

- A. If yes, on average how severe was this problem?
 - **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

19. In the last 2 weeks, did you feel excessively sleepy during the day?

YES INO If NO, please proceed to Question 20.

A. If **yes**, on average how **severe** was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

20. In the last 2 weeks, did you **have painful sensations in your body**? (For example, aching, tightness, burning, sharp, dull or throbbing pain)

		If NO, please proceed to Question 21.
--	--	---------------------------------------

A. If yes, on average how severe was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

21. In the last 2 weeks, did you **have strange sensations in your body**? (For example, tingling or numbness)

- **YES I** NO If NO, please proceed to Question 22.
- A. If yes, on average how severe was this problem?
 - MILD the problem did not affect my ability to carry out normal daily tasks or social activities
 MODERATE the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 SEVERE the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

	OFF	NO DIFFERENCE
--	-----	---------------

22. In the last 2 weeks, did you feel short of breath?

		If NO, please proceed to Question 23.
A. If yes , on average	how severe	was this problem?

- **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
- **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
- **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were **ON** (levodopa was working), or **OFF** (levodopa was not working)?

23. In the last 2 weeks, did you have problems with vision?

(For example, seeing double or things appearing blurry)

		If NO, please proceed to Question 24.
--	--	---------------------------------------

A. If yes, on average how severe was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

24. In the last 2 weeks, did you **have excessive sweating**? (For example, your clothes were damp or stained from sweat more than in the past)

- **YES INO** If NO, please proceed to Question 25.
- A. If yes, on average how severe was this problem?
 - **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

25. In the last 2 weeks, did you **feel that your heart was racing, had skipped a beat, or was pounding**?

- □ YES □ NO If NO, please proceed to Question 26.
- A. If yes, on average how severe was this problem?
 - **MILD** the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

□ ON □ OFF □ NO DIFFERENCE

26. In the last 2 weeks, did you **urinate more frequently or felt you had to go to the bathroom urgently**?

- **YES I** NO If NO, please proceed to Question 27.
- A. If yes, on average how severe was this problem?
 - MILD the problem did not affect my ability to carry out normal daily tasks or social activities
 - **MODERATE** the problem affected but did not prevent me from carrying out normal daily tasks or social activities
 - **SEVERE** the problem prevented me from carrying out normal daily tasks or social activities
- B. Was this problem <u>worse</u> when you were <u>ON</u> (levodopa was working), or <u>OFF</u> (levodopa was not working)?

27. In the last 2 weeks, did you have difficulty having a bowel movement?

A. If yes, on average how severe was this problem?

the problem did not affect my ability to carry out normal daily tasks or social activities
the problem affected but did not prevent me from carrying out normal daily tasks or social activities
the problem prevented me from carrying out normal daily tasks or social activities

B. Was this problem <u>worse</u> when you were <u>**ON**</u> (levodopa was working), or <u>**OFF**</u> (levodopa was not working)?