

International Parkinson and Movement Disorder Society

# **MDS-NMS**

International Parkinson and Movement Disorder Society – Non-Motor Rating Scale

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RATER-ADMINISTERED VERSION

| Patient Name or Date:                                 | Identifier:   |  |                                   |  |  |  |
|---|---|--|-----------------------------------|--|--|--|
| Respondent:   | Patient   | Informant/Caregiver                        | Patient and Informant             |  |  |  |
| Patient's motor s                                     | tate: 🗌 On  | □ Off                                      |                                   |  |  |  |
|   |   | SCORING                                    |                                   |  |  |  |
| Average Frequ   | ency / Duration:  | (percentages denote days                   | per week or hours per waking day) |  |  |  |
| 0: Never  |   |  |                                   |  |  |  |
| 1: Rarely   | (≤ 10% of ti  | me)  |                                   |  |  |  |
| 2: Sometime   | Sometimes (11-25% of time)                                      |  |                                   |  |  |  |
| 3: Frequently   | (26-50% of  | (26-50% of time)                           |                                   |  |  |  |
| 4: Majority of  | : Majority of time (≥ 51% of time)                              |  |                                   |  |  |  |
| Average Sever   | <u>ity</u> :  |  |                                   |  |  |  |
| 0: Not prese  | nt (only if freq  | uency = 0)                                 |                                   |  |  |  |
| 1: Minimal  | 1: Minimal (no distress or disturbance to patient or caregiver) |  |                                   |  |  |  |
| 2: Mild   | (minor distr  | ess or disturbance to patien               | t or caregiver)                   |  |  |  |
| 3: Moderate   | (considerat   | le distress or disturbance to              | patient or caregiver)             |  |  |  |
| 4: Severe   | (major distr  | ess or disturbance to patien               | t or caregiver)                   |  |  |  |
| Calculations:   |   |  |                                   |  |  |  |
| Item Total  | = Fr  | equency multiplied by sev                  | verity                            |  |  |  |
| Subscale Total  | = St  | = Sum of all Item totals for that Subscale |                                   |  |  |  |
| MDS-NMS Total Score = Sum of totals for Subscales A-M |   |  |                                   |  |  |  |

For each question use the following introduction:

"How often have you ... " or "How often has the patient ... "

If the answer to the question is "Never", rate frequency/duration as "0", rate severity also as "0" and move on to the next question.

If the answer to the question is not "Never", then ask:

"When you have had... / When the patient has had... [the symptom], how bad has it been on average?"

When answering questions about an "**increase**" or "**decrease**"/"reduction" in symptoms, use as your comparison point your/the patient's experiences on average as an adult prior to having Parkinson's disease.

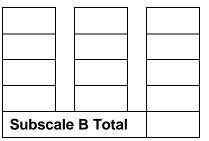
RATER-ADMINISTERED VERSION

## Rate symptoms over past 4 weeks

|  | Frequency<br>(0-4) | Severity<br>(0-4) | Frequency<br>x severity |
|--|--------------------|-------------------|-------------------------|
| A. Depression:                           |                    |                   |                         |
| 1. Felt sad or depressed?                |                    |                   |                         |
| 2. Had difficulty experiencing pleasure? |                    |                   |                         |
| 3. Felt hopeless?                        |                    |                   |                         |
| 4. Had negative thoughts about yourself? |                    |                   |                         |
| 5. Felt that life is not worth living?   |                    |                   |                         |
| -  | Subscal            | e A Total         |                         |

### **B.** Anxiety:

| 1. Felt worried?   |
|--|
| 2. Felt nervous?   |
| 3. Had panic or anxiety attacks?                               |
| 4. Been worried about being in public or in social situations? |
|  |



# C. Apathy:

| 1. Had a reduced motivation to start day-to-day activities? | • |
|---|---|
|---|---|

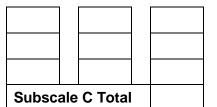
- 2. Had a reduced interest in talking to people? .....
- 3. Had a reduction in experiencing emotions?.....

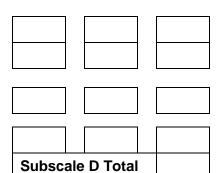
## D. Psychosis:

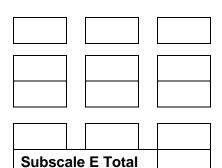
- 1. Sensed things or people in margins of your visual field? (passage or presence phenomena).....
- 2. Visually misinterpreted an actual object? (illusions) .....
- 3. Seen, heard, felt, tasted, or smelled things that other people did not? (hallucinations)
- 4. Believed things to be true that others did not?(e.g., delusions of persecution, jealousy, or misidentification) ......

## E. Impulse Control and Related Disorders:

- 1. Had an increase in gambling, sexual, buying, or eating behaviors?
- 2. Had an increase in other behaviors (e.g., internet use, hobbies, artistic activities, writing, hoarding)?.....
- 3. Repeatedly handled objects without any purpose? (punding) .....
- 4. Routinely taken more anti-parkinsonian medications than prescribed? (dopamine dysregulation syndrome).....







RATER-ADMINISTERED VERSION

## Rate symptoms over past 4 weeks

|   | Frequency<br>(0-4)                    | Severity<br>(0-4) | Frequency x severity                  |
|---|---------------------------------------|-------------------|---------------------------------------|
| F. Cognition:   |                                       |                   |                                       |
| 1. Had difficulty remembering things?   |                                       |                   |                                       |
| 2. Had difficulty learning new things?  |                                       |                   |                                       |
| 3. Had difficulty keeping focus or paying attention?  |                                       |                   |                                       |
| 4. Had difficulty finding words or expressing ideas?  |                                       |                   |                                       |
| 5. Had difficulty planning or carrying out complex tasks, not due to motor problems? (executive abilities)  |                                       |                   |                                       |
| 6. Had difficulty judging the position of things? (visuospatial abilities)  |                                       |                   |                                       |
|   | Subscale                              | F Total           |                                       |
| G. Orthostatic Hypotension:   |                                       |                   |                                       |
| 1. Felt lightheaded or fainted when changing position?  |                                       |                   |                                       |
| 2. Had dizziness or weakness upon standing?   |                                       |                   |                                       |
|   | Subscale                              | e G Total         |                                       |
| H. Urinary:   | · · · · · · · · · · · · · · · · · · · | []                | · · · · · · · · · · · · · · · · · · · |
| 1. Had an urgent need to empty bladder? (urinary urgency)   |                                       |                   |                                       |
| 2. Had to empty bladder more than every 2 hours?<br>(urinary frequency)   |                                       |                   |                                       |
| 3. Had to empty bladder more than twice overnight? (nocturia)   |                                       |                   |                                       |
|   | Subscale                              | e H Total         |                                       |
| I. Sexual:  |                                       |                   |                                       |
| <ol> <li>Had decreased sexual drive or interest in sex?</li> </ol>  |                                       |                   |                                       |
| <ol> <li>Had difficulty with sexual arousal (e.g., erectile dysfunction or<br/>vaginal dryness) or sexual performance not related to motor<br/>problems (e.g., not related to Parkinson's rigidity)?</li> </ol> |                                       |                   |                                       |
|   | Subscale                              | e I Total         |                                       |
| J. Gastrointestinal:  |                                       |                   | <u> </u>                              |
| 1. Had any drooling of saliva?  |                                       |                   |                                       |
|   |                                       |                   |                                       |
| <ol> <li>Had difficulty swallowing?</li> <li>Had nausea or felt sick in the stomach?</li> </ol>   |                                       |                   |                                       |
|   |                                       |                   |                                       |
| 4. Had constipation? (defined as < 3 bowel movements/week)  | Subscale                              | e J Total         |                                       |

RATER-ADMINISTERED VERSION

## Rate symptoms over past 4 weeks

|   | Frequency<br>(0-4) | Severity<br>(0-4) | Frequency x severity |
|---|--------------------|-------------------|----------------------|
| K. Sleep and Wakefulness:   |                    |                   |                      |
| 1. Had difficulty falling asleep or staying asleep? (insomnia)  |                    |                   |                      |
| 2. Acted out dreams while asleep, such as shouting, flailing arms, punching, or running movements? (REM sleep behavior)   |                    |                   |                      |
| <ol> <li>Dozed off or fallen asleep unintentionally during waking hours?<br/>(e.g., during conversation, at mealtimes, or while driving, watching<br/>television; excessive daytime sleepiness)</li> </ol>  |                    |                   |                      |
| 4. Had an irresistible urge to move legs or arms when sitting or<br>lying down which improved with movement? (restlessness)   |                    |                   |                      |
| 5. Had any involuntary jerky movements in arms or legs during sleep<br>or while resting? (periodic limb movements)  |                    |                   |                      |
| 6. Woken at night due to snoring, gasping, or difficulty with breathing?  |                    |                   |                      |
|   |                    | e K Total         |                      |
| L. Pain:  |                    |                   |                      |
| 1. Had muscle, joint, or back pain?   |                    |                   |                      |
| 2. Had a deep or dull aching pain within the body?  |                    |                   |                      |
| 3. Had pain due to abnormal twisting movements of arms or legs or body, often present in the early morning period? (dystonia)   |                    |                   |                      |
| 4. Had other types of pain? (e.g., nocturnal pain, orofacial pain)  |                    |                   |                      |
|   | Subsca             | e L Total         |                      |
| M. Other:   |                    |                   |                      |
| <ol> <li>Had an unintentional weight loss?<br/>(rate frequency as either not present (0) or present (4);<br/>for severity rate 0 (only if frequency = 0), 1 (minimal), 2 (mild),<br/>3 (moderate), or 4 (severe))</li> </ol>                      |                    |                   |                      |
| <ol> <li>Had a decrease in sense of smell? (impaired olfaction)<br/>(rate frequency as either not present (0) or present (4);<br/>for severity rate 0 (only if frequency = 0), 1 (minimal), 2 (mild),<br/>3 (moderate), or 4 (severe))</li> </ol> |                    |                   |                      |
| 3. Felt excessively physically tired? (physical fatigue)  |                    |                   |                      |
| 4. Felt excessively mentally tired? (mental fatigue)  |                    |                   |                      |
| 5. Had excessive sweating not related to temperature?   |                    |                   |                      |
|   | Subscal            | e M Total         |                      |
|   |                    |                   |                      |

MDS-NMS TOTAL SCORE

RATER-ADMINISTERED VERSION

### Rate symptoms over past 4 weeks

## MDS-NMS Non-Motor Fluctuations (NMF) Subscale

Do you / Does the patient experience changes in non-motor symptoms (as listed below) in relation to the timing of anti-parkinsonian medications (i.e., symptoms occurring or worsening during "Off" period)?

Yes No

If no, MDS-NMS NMF Total Score (below) = 0

If yes, please complete the following section:

|   | SCORING   |   |  |  |  |
|---|---|---|--|--|--|
| Typ   | Typical degree of change from "On" to "Off" period: |   |  |  |  |
| 0:  | No change   |   |  |  |  |
| 1:  | Minimal   |   |  |  |  |
| 2:  | Small   |   |  |  |  |
| 3:  | Medium  |   |  |  |  |
| 4:  | Large   |   |  |  |  |
| Subscore "Change" = Sum of all "Degree of change" items |   |   |  |  |  |
| MD  | S-NMS NMF Total Score                               | = Subscore "Change" multiplied by Subscore "Time" |  |  |  |

# Degree of change

(0-4)

| 1. Depression (as listed in Subscale A)                      |  |
|--|--|
| 2. Anxiety (as listed in Subscale B)                         |  |
| 3. Thinking or cognitive abilities (as listed in Subscale F) |  |
| 4. Bladder symptoms (as listed Subscale H)                   |  |
| 5. Restlessness (as listed in Subscale K, item 4)            |  |
| 6. Pain (as listed in Subscale L)                            |  |
| 7. Fatigue (as listed in Subscale M, items 3 and 4)          |  |
| 8. Excessive sweating (as listed in Subscale M, item 5)      |  |

#### Time spent in non-motor "Off" state:

- 1: Rarely  $(\leq 10\% \text{ of waking day})$
- 2: Sometimes (11-25% of waking day)
- 3: Frequently (26-50% of waking day)
- 4: Majority of time ( $\geq$  51% of waking day)

MDS-NMS NMF Subscore "Change"

MDS-NMS NMF Subscore "Time"



| MDS-NMS Score Sheet                    |   |       |  |  |  |  |  |
|--|---|-------|--|--|--|--|--|
| RATER-ADMINISTERED VERSION             |   |       |  |  |  |  |  |
| Subsca                                 | Item Total = Frequency multiplied by Severity<br>Subscale Total = Sum of all Item Totals for that Subscale<br>MDS-NMS Total Score = Sum of Totals for Subscales A-M |       |  |  |  |  |  |
| Respondent:                            | Respondent:  Patient  Informant/Caregiver  Patient and Informant  |       |  |  |  |  |  |
| Patient's motor state:                 | ∐ On  | □ Off |  |  |  |  |  |
| A. Depression Frequency Severity Total |   |       |  |  |  |  |  |
| 1. Sad or depressed                    |   |       |  |  |  |  |  |
| 2. Experiencing pleasure               |   |       |  |  |  |  |  |
| 3. Hopelessness                        |   |       |  |  |  |  |  |
| 4. Negative thoughts                   |   |       |  |  |  |  |  |
| 5. Life not worth living               |   |       |  |  |  |  |  |
| Depression Subscale Total              |   |       |  |  |  |  |  |
|  |   |       |  |  |  |  |  |

| B. Anxiety                  | Frequency | Severity | Total |
|-----------------------------|-----------|----------|-------|
| 1. Worried                  |           |          |       |
| 2. Nervous                  |           |          |       |
| 3. Panic or anxiety attacks |           |          |       |
| 4. Social phobia            |           |          |       |
| Anxiety Subscale Total      |           |          |       |

| C. Apathy              | Frequency | Severity | Total |  |
|------------------------|-----------|----------|-------|--|
| 1. Interest activities |           |          |       |  |
| 2. Interest talking    |           |          |       |  |
| 3. Emotions            |           |          |       |  |
| Apathy Subscale Total  |           |          |       |  |

| D. Psychosis                     | Frequency | Severity | Total |
|----------------------------------|-----------|----------|-------|
| 1. Passage or presence phenomena |           |          |       |
| 2. Illusions                     |           |          |       |
| 3. Hallucinations                |           |          |       |
| 4. Delusions                     |           |          |       |
| Psychosis Subscale Total         |           |          |       |

| E. Impulse Control and Related Disorders             | Frequency | Severity | Total |
|--|-----------|----------|-------|
| 1. Impulse control disorders                         |           |          |       |
| 2. Other compulsive behaviors                        |           |          |       |
| 3. Punding   |           |          |       |
| 4. Dopamine dysregulation syndrome                   |           |          |       |
| Impulse Control and Related Disorders Subscale Total |           |          |       |

| F. Cognition                   | Frequency | Severity | Total |
|--------------------------------|-----------|----------|-------|
| 1. Remembering                 |           |          |       |
| 2. Learning new information    |           |          |       |
| 3. Focus or attention          |           |          |       |
| 4. Find words or express ideas |           |          |       |
| 5. Executive abilities         |           |          |       |
| 6. Visuospatial abilities      |           |          |       |
| Cognition Subscale Total       |           |          |       |

| G. Orthostatic Hypotension             | Frequency | Severity | Total |
|--|-----------|----------|-------|
| 1. Lightheaded or fainted              |           |          |       |
| 2. Dizziness or weakness               |           |          |       |
| Orthostatic Hypotension Subscale Total |           |          |       |

| H. Urinary             | Frequency | Severity | Total |
|------------------------|-----------|----------|-------|
| 1. Urinary urgency     |           |          |       |
| 2. Urinary frequency   |           |          |       |
| 3. Nocturia            |           |          |       |
| Urinary Subscale Total |           |          |       |

| I. Sexual                        | Frequency | Severity | Total |
|----------------------------------|-----------|----------|-------|
| 1. Sex drive or interest         |           |          |       |
| 2. Sexual arousal or performance |           |          |       |
| Sexual Subscale Total            |           |          |       |

| J. Gastrointestinal             | Frequency | Severity | Total |
|---------------------------------|-----------|----------|-------|
| 1. Drooling                     |           |          |       |
| 2. Swallowing                   |           |          |       |
| 3. Nausea or sick in stomach    |           |          |       |
| 4. Constipation                 |           |          |       |
| Gastrointestinal Subscale Total |           |          |       |

| K. Sleep and Wakefulness             | Frequency | Severity | Total |
|--------------------------------------|-----------|----------|-------|
| 1. Insomnia                          |           |          |       |
| 2. REM sleep behavior                |           |          |       |
| 3. Dozing off                        |           |          |       |
| 4. Restlessness                      |           |          |       |
| 5. Periodic limb movements           |           |          |       |
| 6. Snoring or difficulty breathing   |           |          |       |
| Sleep and Wakefulness Subscale Total |           |          |       |

| L. Pain                     | Frequency | Severity | Total |
|-----------------------------|-----------|----------|-------|
| 1. Muscle, joint, back pain |           |          |       |
| 2. Deep or dull pain        |           |          |       |
| 3. Dystonia                 |           |          |       |
| 4. Other pain               |           |          |       |
| Pain Subscale Total         |           |          |       |

| M. Other              | Frequency | Severity | Total |
|-----------------------|-----------|----------|-------|
| 1. Weight loss        |           |          |       |
| 2. Decreased smell    |           |          |       |
| 3. Physical fatigue   |           |          |       |
| 4. Mental fatigue     |           |          |       |
| 5. Excessive sweating |           |          |       |
| Other Subscale Total  |           |          |       |

# **MDS-NMS TOTAL SCORE**

# MDS-NMS Score Sheet – Non Motor Fluctuations

Subscore "Change" = Sum of all "degree of change" items Subscore "Time" = Time spent in non-motor "Off" state MDS-NMS NMF Total Score = Subscore "Change" multiplied by Subscore "Time"

| NON-MOTOR FLUCTUATIONS<br>(optional) | Typical degree of<br>change from "On" to<br>"Off" period |
|--------------------------------------|--|
| 1. Depression                        |  |
| 2. Anxiety                           |  |
| 3. Thinking or cognitive abilities   |  |
| 4. Bladder symptoms                  |  |
| 5. Restlessness                      |  |
| 6. Pain                              |  |
| 7. Fatigue                           |  |
| 8. Excessive sweating                |  |
| Subscore "Change"                    |  |

Subscore "Time"

# MDS-NMS NON-MOTOR FLUCTUATIONS TOTAL SCORE

# **Glossary of Terms**

- A. Depression: a mood disorder characterized by sustained change in emotions (sadness, decreased interest or pleasure), cognition (negative thoughts about life or self, such as hopelessness, helplessness, indecisiveness, or death or suicide ideation) or behavior (isolative, withdrawn, sleep disturbances, appetite disturbances)
- **B. Anxiety**: an affective disorder characterized by sustained excessive worrying which can be (1) generalized and include symptoms such as restlessness, being easily fatigued, mind going blank or trouble concentrating, irritability, and muscle tension; (2) specific anxiety or panic attacks; (3) fear of being in public (agoraphobia); or (4) fear of being in social situations (social phobia)

**Anxiety or panic attack**: an abrupt surge of intense fear or intense discomfort, can include shortness of breath, heart beating fast, upset stomach, sweating, dizziness or faintness, sensation of chill or heat, or sense something bad is going to happen or even a sense of dying

- **C. Apathy**: a disorder characterized by decreased motor activity (less initiation of motor activity not due to parkinsonism), emotional expression (less emotional engagement separate from decreased facial expression due to parkinsonism), or speech (less likely to initiate or engage in conversation)
- **D. Psychosis**: a disorder characterized by changes in perception (passage or presence phenomena, illusions, or hallucinations) or thought (delusions)

**Passage phenomenon**: visual sensation of something moving in periphery of visual field **Presence phenomenon**: visual sensation of person being in periphery of visual field **Illusions**: visual misinterpretation of an actual object

**Hallucinations**: a sensory (visual, auditory, taste, smell, or feeling) experience that is not real or experienced by other people

**Delusions**: a belief that something is true for which there is no objective evidence and which other persons do not hold true

- E. Impulse control disorders: a failure to resist an impulse or drive that leads to repeated engagement in activities that become harmful to self or others; <u>compared with pre-PD behavior</u>
   Hoarding: the needless collection of objects and an inability to get rid of them
   Punding: the needless or purposeless repetition of a simple motor activity
   Dopamine dysregulation syndrome: taking an excess (beyond what is prescribed) of Parkinson's disease medications for their motor or psychological effects, often with significant mood changes during "on" (irritability, hypomania) or "off" (dysphoria) states
- F. Cognition: the activities of thinking, understanding, learning, and remembering
   Attention: concentrating on one part of the environment while ignoring other things
   Executive abilities: cognitive processes involved in maintaining multiple pieces of information in the mind at the same time, reasoning, task flexibility, problem solving, and task planning and execution

Visuospatial abilities: ability relating to visual perception of spatial relationships among objects

**G.** Orthostatic hypotension: a drop in blood pressure severe enough to cause symptoms when changing from sitting to standing position or from lying to sitting position

#### H. Urinary

Nocturia: excessive urination at night, defined as more than 2 times overnight

#### I. Sexual

**Erectile dysfunction**: inability of a man to maintain an erection sufficient for satisfying sexual activity

### J. Gastrointestinal: relating to the stomach and intestines

Saliva: watery liquid secreted into the mouth by glands, providing lubrication for chewing and swallowing, and aiding digestion
Swallowing: difficulty swallowing including liquids and solids, as well as choking while swallowing
Nausea: a feeling of sickness with a tendency to vomit
Constipation: infrequent bowel movements (usually less than three bowel movements per week) or difficult passage of stools

### K. Sleep and wakefulness

**Insomnia**: difficultly falling asleep or staying asleep **Rapid eye movement (REM) sleep**: a stage in the normal sleep cycle during which dreams occur and the body undergoes marked changes including rapid eye movement, loss of reflexes, and increased pulse rate and brain activity

#### L. Pain

**Dystonia**: a state of abnormal muscle tone resulting in muscular spasm and abnormal posture **Nocturnal pain**: pain overnight **Orofacial pain**: pain which is felt in the mouth, jaws, or face

#### M. Other

Olfaction: the action or capacity of smelling

**Fatigue (physical)**: state of excessive physical weariness or exhaustion (after physical exertion), different from sleepiness

Fatigue (mental): state of excessive mental weariness or exhaustion, different from sleepiness