

**International Parkinson's Disease and Movement Disorder Society –
Non-Motor Rating Scale (MDS-NMS) – Phase 3**

Logo of respective institution

**International Parkinson's Disease and Movement Disorder
Society –
Non-Motor Rating Scale (MDS-NMS)
Phase 3**

**Case Report Form
Baseline data- patient based**

Patient's Name Initials	
Patient Serial Number	

Principal Investigator Code	
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Date	Day:	Month:	Year:
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1. The MDS-UPDRS – patient based

Patient Questionnaire:

Instructions:

This questionnaire will ask you about your experiences of daily living.

There are 20 questions. We are trying to be thorough, and some of these questions may therefore not apply to you now or ever. If you do not have the problem, simply mark 0 for NO.

Please read each one carefully and read all answers before selecting the one that best applies to you.

We are interested in your average or usual function over the past week including today. Some patients can do things better at one time of the day than at others. However, only one answer is allowed for each question, so please mark the answer that best describes what you can do most of the time.

You may have other medical conditions besides Parkinson's disease. Do not worry about separating Parkinson's disease from other conditions. Just answer the question with your best response.

Use only 0, 1, 2, 3, 4 for answers, nothing else. Do not leave any blanks.

Your doctor or nurse can review the questions with you, but this questionnaire is for patients to complete, either alone or with their caregivers.

Who is filling out this questionnaire (check the best answer):

☐

Patient

☐

Caregiver

☐

Patient and Caregiver in Equal Proportion

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Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)		SCORE
<p>1.7 SLEEP PROBLEMS</p> <p>Over the past week, have you had trouble going to sleep at night or staying asleep through the night? Consider how rested you felt after waking up in the morning.</p> <p>0: Normal: No problems.</p> <p>1: Slight: Sleep problems are present but usually do not cause trouble getting a full night of sleep.</p> <p>2: Mild: Sleep problems usually cause some difficulties getting a full night of sleep.</p> <p>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.</p> <p>4: Severe: I usually do not sleep for most of the night.</p>	<input type="text"/>	
<p>1.8 DAYTIME SLEEPINESS</p> <p>Over the past week, have you had trouble staying awake during the daytime?</p> <p>0: Normal: No daytime sleepiness.</p> <p>1: Slight: Daytime sleepiness occurs but I can resist and I stay awake.</p> <p>2: Mild: Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV.</p> <p>3: Moderate: I sometimes fall asleep when I should not. For example, while eating or talking with other people.</p> <p>4: Severe: I often fall asleep when I should not. For example, while eating or talking with other people.</p>	<input type="text"/>	

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	SCORE
<p>1.9 PAIN AND OTHER SENSATIONS</p> <p>Over the past week, have you had uncomfortable feelings in your body like pain, aches tingling or cramps?</p> <p>0: Normal: No uncomfortable feelings.</p> <p>1: Slight: I have these feelings. However, I can do things and be with other people without difficulty.</p> <p>2: Mild: These feelings cause some problems when I do things or am with other people.</p> <p>3: Moderate: These feelings cause a lot of problems, but they do not stop me from doing things or being with other people.</p> <p>4: Severe: These feelings stop me from doing things or being with other people.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>1.10 URINARY PROBLEMS</p> <p>Over the past week, have you had trouble with urine control? For example, an urgent need to urinate, a need to urinate too often, or urine accidents?</p> <p>0: Normal: No urine control problems.</p> <p>1: Slight: I need to urinate often or urgently. However, these problems do not cause difficulties with my daily activities.</p> <p>2: Mild: Urine problems cause some difficulties with my daily activities. However, I do not have urine accidents.</p> <p>3: Moderate: Urine problems cause a lot of difficulties with my daily activities, including urine accidents.</p> <p>4: Severe: I cannot control my urine and use a protective garment or have a bladder tube.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>

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	SCORE
<p>1.11 CONSTIPATION PROBLEMS</p> <p>Over the past week have you had constipation troubles that cause you difficulty moving your bowels?</p> <p>0: Normal: No constipation.</p> <p>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.</p> <p>2: Mild: Constipation causes me to have some troubles doing things or being comfortable.</p> <p>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.</p> <p>4: Severe: I usually need physical help from someone else to empty my bowels.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>1.12 LIGHT HEADEDNESS ON STANDING</p> <p>Over the past week, have you felt faint, dizzy or foggy when you stand up after sitting or lying down?</p> <p>0: Normal: No dizzy or foggy feelings.</p> <p>1: Slight: Dizzy or foggy feelings occur. However, they do not cause me troubles doing things.</p> <p>2: Mild: Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down.</p> <p>3: Moderate: Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling.</p> <p>4: Severe: Dizzy or foggy feelings cause me to fall or faint.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>

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1.13 FATIGUE		SCORE
<p>Over the past week, have you usually felt fatigued? This feeling is <u>not</u> part of being sleepy or sad</p> <p>0: Normal: No fatigue.</p> <p>1: Slight: Fatigue occurs. However it does not cause me troubles doing things or being with people.</p> <p>2: Mild: Fatigue causes me some troubles doing things or being with people.</p> <p>3: Moderate: Fatigue causes me a lot of troubles doing things or being with people. However, it does not stop me from doing anything.</p> <p>4: Severe: Fatigue stops me from doing things or being with people.</p>		<input type="text"/>
Part II: Motor Aspects of Experiences of Daily Living (M-EDL)		
<p>2.1 SPEECH</p> <p>Over the past week, have you had problems with your speech?</p> <p>0: Normal: Not at all (no problems).</p> <p>1: Slight: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.</p> <p>2: Mild: My speech causes people to ask me to occasionally repeat myself, but not everyday.</p> <p>3: Moderate: My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood.</p> <p>4: Severe: Most or all of my speech cannot be understood.</p>		<input type="text"/>

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	SCORE
<p>2.2 SALIVA & DROOLING</p> <p>Over the past week, have you usually had too much saliva during when you are awake or when you sleep?</p> <p>0: Normal: Not at all (no problems).</p> <p>1: Slight: I have too much saliva, but do not drool.</p> <p>2: Mild: I have some drooling during sleep, but none when I am awake.</p> <p>3: Moderate: I have some drooling when I am awake, but I usually do not need tissues or a handkerchief.</p> <p>4: Severe: I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>2.3 CHEWING AND SWALLOWING</p> <p>Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped or blended to avoid choking?</p> <p>0: Normal: No problems.</p> <p>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.</p> <p>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.</p> <p>3: Moderate. I choked at least once in the past week.</p> <p>4: Severe: Because of chewing and swallowing problems, I need a feeding tube.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>

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	SCORE
<p>2.4 EATING TASKS</p> <p>Over the past week, have you usually had troubles handling your food and using eating utensils? For example, do you have trouble handling finger foods or using forks, knives, spoons, chopsticks?</p> <p>0: Normal: Not at all (No problems).</p> <p>1: Slight: I am slow, but I do not need any help handling my food and have not had food spills while eating.</p> <p>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.</p> <p>3: Moderate: I need help with many eating tasks but can manage some alone.</p> <p>4: Severe: I need help for most or all eating tasks.</p>	<div data-bbox="1344 604 1427 686" style="border: 1px solid black; width: 50px; height: 40px; margin: 0 auto;"></div>
<p>2.5 DRESSING</p> <p>Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewelry?</p> <p>0: Normal: Not at all (no problems).</p> <p>1: Slight: I am slow but I do not need help.</p> <p>2: Mild: I am slow and need help for a few dressing tasks (buttons, bracelets).</p> <p>3: Moderate: I need help for many dressing tasks.</p> <p>4: Severe: I need help for most or all dressing tasks.</p>	<div data-bbox="1344 1507 1427 1589" style="border: 1px solid black; width: 50px; height: 40px; margin: 0 auto;"></div>

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<p>2.6 HYGIENE</p> <p>Over the past week, have you usually been slow or do you need help with washing, bathing, shaving, brushing teeth, combing your hair or with other personal hygiene?</p> <p>0: Normal: Not at all (no problems).</p> <p>1: Slight: I am slow but I do not need any help.</p> <p>2: Mild: I need someone else to help me with some hygiene tasks.</p> <p>3: Moderate: I need help for many hygiene tasks.</p> <p>4: Severe: I need help for most or all of my hygiene tasks.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>2.7 HANDWRITING</p> <p>Over the past week, have people usually had trouble reading your handwriting?</p> <p>0: Normal: Not at all (no problems).</p> <p>1: Slight: My writing is slow, clumsy or uneven, but all words are clear.</p> <p>2: Mild: Some words are unclear and difficult to read.</p> <p>3: Moderate: Many words are unclear and difficult to read.</p> <p>4: Severe: Most or all words cannot be read.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>2.8 DOING HOBBIES AND OTHER ACTIVITIES</p> <p>Over the past week, have you usually had trouble doing your hobbies or other things that you like to do?</p> <p>0: Normal: Not at all (no problems).</p> <p>1: Slight: I am a bit slow but do these activities easily.</p> <p>2: Mild: I have some difficulty doing these activities.</p> <p>3: Moderate: I have major problems doing these activities, but still do most.</p> <p>4: Severe: I am unable to do most or all of these activities.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>

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<p>2.9 TURNING IN BED</p> <p>Over the past week, do you usually have trouble turning over in bed?</p> <p>0: Normal: Not at all (no problems).</p> <p>1: Slight: I have a bit of trouble turning, but I do not need any help.</p> <p>2: Mild: I have a lot of trouble turning and need occasional help from someone else.</p> <p>3: Moderate: To turn over I often need help from someone else.</p> <p>4: Severe: I am unable to turn over without help from someone else.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>2.10 TREMOR</p> <p>Over the past week, have you usually had shaking or tremor?</p> <p>0: Normal: Not at all. I have no shaking or tremor.</p> <p>1: Slight: Shaking or tremor occurs but does not cause problems with any activities.</p> <p>2: Mild: Shaking or tremor causes problems with only a few activities.</p> <p>3: Moderate: Shaking or tremor causes problems with many of my daily activities.</p> <p>4: Severe: Shaking or tremor causes problems with most or all activities.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>2.11 GETTING OUT OF BED, A CAR, OR A DEEP CHAIR</p> <p>Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair?</p> <p>0: Normal: Not at all (no problems).</p> <p>1: Slight: I am slow or awkward, but I usually can do it on my first try.</p> <p>2: Mild: I need more than one try to get up or need occasional help.</p> <p>3: Moderate: I sometimes need help to get up, but most times I can still do it on my own.</p> <p>4: Severe: I need help most or all of the time.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>

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<p>2.12 WALKING AND BALANCE</p> <p>Over the past week, have you usually had problems with balance and walking?</p> <p>0: Normal: Not at all (no problems).</p> <p>1: Slight: I am slightly slow or may drag a leg. I never use a walking aid.</p> <p>2: Mild: I occasionally use a walking aid, but I do not need any help from another person.</p> <p>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.</p> <p>4: Severe: I usually use the support of another persons to walk safely without falling.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>2.13 FREEZING</p> <p>Over the past week, on your usual day when walking, do you suddenly stop or freeze as if your feet are stuck to the floor.</p> <p>0: Normal: Not at all (no problems).</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>4: Severe: Because of freezing, most or all of the time, I need to use a walking aid or someone's help.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p>This completes the questionnaire. We may have asked about problems you do not even have, and may have mentioned problems that you may never develop at all. Not all patients develop all these problems, but because they can occur, it is important to ask all the questions to every patient. Thank you for your time and attention in completing this questionnaire.</p>	

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2. PGIS (Patient Global Impression of Severity)

Regarding your condition as a whole, how severe do you feel it is at present?

0	Normal; no symptoms at all
1	Minimal
2	Mild
3	Moderate
4	Severe
5	Very severe