

# MDS-revised UPDRS Part I: Non-Motor Aspects of Experiences of Daily Living

## Part 1A: Complex Behaviors

Primary source of information:

☐ Patient

☐ Caregiver

☐ Patient and Caregiver in Equal Proportion

**To be read to the patient:** I am going to ask you six questions about behaviors that you may or may not experience. Some questions concern common problems and some concern uncommon ones. If you have a problem in one of the areas, please choose the best response that describes how you have felt MOST OF THE TIME during the PAST WEEK. If you are not bothered by a problem, you can simply respond NO. I am trying to be thorough, so I may ask questions that have nothing to do with you.

**1.1 Cognitive Impairment** (Over the past week have you had problems remembering things, following conversations, paying attention, thinking clearly, or finding your way around the house or in town?)

**0: Normal:** 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 ability to carry out normal activities and social interactions.

**3: Moderate:** Cognitive deficits interfere with but do not preclude 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** (Over the past week, have you seen, heard, smelled, or felt things that were not really there?)

**0: Normal:** No hallucinations or psychotic behavior

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

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

**3: Moderate:** Formed hallucinations with loss of insight.

**4: Severe:** Patient has delusions or paranoia.

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<p><b>1.3 Depressed Mood</b> (Over the past week, have you felt low, sad, hopeless, or unable to enjoy things? If yes, was this feeling for longer than one day at a time? Did it make it difficult for you to carry out your usual activities or to be with people?)</p> <p><b>0: Normal:</b> No depressed mood</p> <p><b>1: Slight:</b> Episodes of depressed mood that are not sustained for more than one day at a time. No interference with the patient's ability to carry out normal activities and social interactions</p> <p><b>2: Mild:</b> Depressed mood that is sustained over days, but without interference with normal activities and social interactions.</p> <p><b>3: Moderate:</b> Depressed mood that interferes with, but does not preclude the patient's ability to carry out normal activities and social interactions.</p> <p><b>4: Severe:</b> Depressed mood precludes the patient's ability to carry out normal activities and social interactions</p>	<p><b>1.4 Anxious Mood</b> (Over the past week, have you felt nervous, worried, or tense? If yes, was this feeling for longer than one day at a time? Did it make it difficult for you to follow your usual activities or to be with other people?)</p> <p><b>0: Normal:</b> No anxious feelings</p> <p><b>1: Slight:</b> Anxious feeling present but not sustained for more than one day at a time. No interference with the patient's ability to carry out normal activities and social interactions</p> <p><b>2: Mild:</b> Anxious feelings are sustained over more than one day at a time, but without interference with the patient's ability to carry out normal activities and social interactions.</p> <p><b>3: Moderate:</b> Anxious feeling interfere with, but do not preclude the patient's ability to carry out normal activities and social interactions.</p> <p><b>4: Severe:</b> Anxious feelings preclude the patient's ability to carry out normal activities and social interactions</p>
<p><b>1.5 Apathy</b> (Over the past week, have you felt indifferent to doing activities or being with people?)</p> <p><b>0: Normal:</b> No apathy</p> <p><b>1: Slight:</b> Apathy appreciated by patient or caregiver with no concrete interference with the patient's ability to carry out normal activities and social interactions</p> <p><b>2: Mild:</b> Apathy interferes with isolated activities and social interactions.</p> <p><b>3: Moderate:</b> Apathy interferes with most activities and social interactions.</p> <p><b>4: Severe:</b> Passive and withdrawn, complete loss of initiative.</p>	<p><b>1.6 Features of Dopamine Dysregulation Syndrome</b> (Over the past week, have you had unusually strong urges that are hard to control? Do you feel driven to do or think about something and find it hard to stop?)</p> <p><b>0: Normal:</b> No problems present</p> <p><b>1: Slight:</b> Problems are present but usually do not cause any difficulties for the patient or family/caregiver.</p> <p><b>2: Mild:</b> Problems are present and usually cause a few difficulties in the patients' personal and family life.</p> <p><b>3: Moderate:</b> Problems are present and usually cause a lot of difficulties in the patient's personal and family life.</p> <p><b>4: Severe:</b> Problems are present and preclude the patient's ability to carry out normal activities or social interactions or to maintain previous standards in personal and family life.</p>

## **MDS-revised UPDRS Part I - II: 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 other. 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

**Questionnaire begins on next page**

Part I: Non-motor Aspects of Experiences of Daily Living	
<p><b>1.7 Sleep Problems</b> 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><b>0: Normal:</b> No problems.</p> <p><b>1: Slight:</b> Sleep problems are present but usually do not cause trouble getting a full night of sleep.</p> <p><b>2: Mild:</b> Sleep problems usually cause some difficulties getting a full night of sleep.</p> <p><b>3: Moderate:</b> 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><b>4: Severe:</b> I usually do not sleep for most of the night.</p>	<p><b>1.8 Daytime Sleepiness</b> Over the past week, have you had trouble staying awake during the daytime?</p> <p><b>0: Normal:</b> No daytime sleepiness.</p> <p><b>1: Slight:</b> Daytime sleepiness occurs but I can resist and I stay awake.</p> <p><b>2: Mild:</b> Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV.</p> <p><b>3: Moderate:</b> I sometimes fall sleep when I should not. For example, while eating or talking with other people.</p> <p><b>4: Severe:</b> I often fall asleep when I should not. For example, while eating or talking with other people.</p>
<p><b>1.9 Pain and other Sensations</b> Over the past week, have you had uncomfortable feelings in your body like pain, aches, tingling, or cramps?</p> <p><b>0: Normal:</b> No uncomfortable feelings.</p> <p><b>1: Slight:</b> I have these feeling. However, I can do things and be with other people without difficulty.</p> <p><b>2: Mild:</b> These feelings cause some problems when I do things or am with other people.</p> <p><b>3: Moderate:</b> These feelings cause a lot of problems, but they do not stop me from doing things or being with other people.</p> <p><b>4: Severe:</b> These feelings stop me from doing things or being with other people.</p>	<p><b>1.10 Urinary Problems</b> 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><b>0: Normal:</b> No urine control problems.</p> <p><b>1: Slight:</b> I need to urinate often or urgently. However, these problems do not cause difficulties with my daily activities.</p> <p><b>2: Mild:</b> Urine problems cause difficulties with my daily activities. However, I do not have urine accidents.</p> <p><b>3: Moderate:</b> Urine problems cause a lot of difficulties with my daily activities, including urine accidents</p> <p><b>4: Severe:</b> I cannot control my urine and use a protective garment or have a bladder tube.</p>
<p><b>1.11 Constipation Problems</b> Over the past week, have you had constipation troubles that cause you difficulty moving your bowels?</p> <p><b>0: Normal:</b> No constipation.</p> <p><b>1: Slight:</b> 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><b>2: Mild:</b> constipation causes me to have some troubles doing things or be comfortable.</p> <p><b>3: Moderate:</b> 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><b>4: Severe:</b> I usually need physical help from someone else to empty my bowels.</p>	<p><b>1.12 Light Headedness on Standing</b> Over the past week, have you felt faint, dizzy or foggy when you stand up after sitting or lying down?</p> <p><b>0: Normal:</b> No dizzy or foggy feelings.</p> <p><b>1: Slight:</b> Dizzy or foggy feelings occur. However, they do not cause me troubles doing things.</p> <p><b>2: Mild:</b> Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down.</p> <p><b>3: Moderate:</b> Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling.</p> <p><b>4: Severe:</b> Dizzy or foggy feelings cause me to fall or faint.</p>

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**1.13 Fatigue**

Over the past week, have you usually felt fatigued? This feeling is not part of being sleepy or sad.

**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.

**Part II: Motor Aspects of Experiences of Daily Living**
**2.1 Speech**

Over the past week, have you had problems with your speech?

**0: Normal:** Not at all.

**1: Slight:** my speech is soft, slurred or uneven, but it does not cause other to ask me to repeat myself.

**2: Mild:** My speech cause 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.

**2.2 Saliva & Drooling**

Over the past week, have you usually had too much saliva when you are awake or when you sleep?

**0: Normal:** Not at all.

**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**

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 be made soft, chopped or blended to avoid choking?

**0: Normal:** Not at all.

**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 problem, I need a feeding tube.

**2.4 Eating Tasks**

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?

**0: Normal:** Not at all.

**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.

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<p><b>2.5 Dressing</b> 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><b>0: Normal:</b> Not at all.</p> <p><b>1: Slight:</b> I am slow but I do not need help.</p> <p><b>2: Mild:</b> I am slow and need help for a few dressing tasks (buttons, bracelets).</p> <p><b>3: Moderate:</b> I need help for many dressing tasks.</p> <p><b>4: Severe:</b> I need help for most or all dressing tasks.</p>	<p><b>2.6 Hygiene</b> 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><b>0: Normal:</b> Not at all.</p> <p><b>1: Slight:</b> I am slow but I do not need any help.</p> <p><b>2: Mild:</b> I need someone else to help me with some hygiene tasks.</p> <p><b>3: Moderate:</b> I need help from many hygiene tasks.</p> <p><b>4: Severe:</b> I need help for most or all of my hygiene tasks.</p>
<p><b>2.7 Handwriting</b> Over the past week, have people usually had trouble reading your handwriting?</p> <p><b>0: Normal:</b> Not at all.</p> <p><b>1: Slight:</b> My writing is slow, clumsy, or uneven, but all words are clear.</p> <p><b>2: Mild:</b> Some words are unclear and difficult to read.</p> <p><b>3: Moderate:</b> Many words are unclear and difficult to read.</p> <p><b>4: Severe:</b> Most or all words cannot be read.</p>	<p><b>2.8 Doing Hobbies and other Activities</b> Over the past week, have you usually had trouble doing your hobbies or other things that you like to do?</p> <p><b>0: Normal:</b> Not at all.</p> <p><b>1: Slight:</b> I am a bit slow but do these activities easily.</p> <p><b>2: Mild:</b> I have some difficulty doing these activities.</p> <p><b>3: Moderate:</b> I have major problems doing these activities, but still do most.</p> <p><b>4: Severe:</b> I am unable to do most or all of these activities.</p>
<p><b>2.9 Turning in Bed</b> Over the past week, do you usually have trouble turning over in bed?</p> <p><b>0: Normal:</b> Not at all.</p> <p><b>1: Slight:</b> I have a bit of trouble turning, but I do not need any help.</p> <p><b>2: Mild:</b> I have a lot of trouble turning and need occasional help from someone else.</p> <p><b>3: Moderate:</b> To turn over I often need help from someone else.</p> <p><b>4: Severe:</b> I am unable to turn over without the help from someone else.</p>	<p><b>2.10 Tremor</b> Over the past week, have you usually had shaking or tremor?</p> <p><b>0: Normal:</b> Not at all.</p> <p><b>1: Slight:</b> Shaking or tremor occurs but does not cause problems with any activities.</p> <p><b>2: Mild:</b> Shaking or tremor causes problems with only a few activities.</p> <p><b>3: Moderate:</b> Shaking or tremor causes problems with many of my daily activities.</p> <p><b>4: Severe:</b> Shaking or tremor cause problems with most or all activities.</p>

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<p><b>2.11 Getting out of Bed, a Car, or a Deep Chair</b> Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair?</p> <p><b>0: Normal:</b> Not at all.</p> <p><b>1: Slight:</b> I am slow or awkward, but I usually can do it on my first try.</p> <p><b>2: Mild:</b> I need more than one try to get up or need occasional help.</p> <p><b>3: Moderate:</b> I sometimes need help to get up, but most times I can still do it on my own.</p> <p><b>4: Severe:</b> I need help most or all of the time.</p>	<p><b>2.12 Walking and Balance</b> Over the past week, have you usually had problems with balance and walking?</p> <p><b>0: Normal:</b> Not at all</p> <p><b>1: Slight:</b> I am slightly slow or may drag a leg. I never use a walking aid.</p> <p><b>2: Mild:</b> I occasionally use a walking aid, but I do not need any help from another person.</p> <p><b>3: Moderate:</b> 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><b>4: Severe:</b> I usually use the support of another person to walk safely without falling.</p>
<p><b>2.13 Freezing</b> 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><b>0: Normal:</b> Not at all</p> <p><b>1: Slight:</b> 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><b>2: Mild:</b> I freeze and have 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><b>3: Moderate:</b> 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><b>4: Severe:</b> Because of freezing, most or all of the time, I need to use a walking aid or someone's help.</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.**