

# Unified Dyskinesia Rating Scale

Unified Dyskinesia Rating Scale (UDysRS) Overview: The Unified Dyskinesia Rating Scale (UDysRS) is developed to evaluate involuntary movements often associated with treated Parkinson's disease. There are two primary sections: • Historical [Part 1 (On-Dyskinesia) and Part 2 (Off-Dystonia)] • Objective [Part 3 (Impairment) and Part 4 (Disability)] On-Dyskinesia refers to the choreic and dystonic movements described to the patient as “jerking or twisting movements that occur when your medicine is working.” Off-Dystonia should be described to the patient as “spasms or cramps that can be painful and occur when your Parkinson's disease medications are not taken or are not working. Throughout the assessment, the focus is on these two forms of movements and a continual emphasis must be placed on excluding from the evaluation the impact of parkinsonism itself and tremor from the ratings. Part I: On-Dyskinesia Ratings: Instructions for the rater This portion of the scale assesses the presence and impact of on-dyskinesia on patients' experiences of daily living. There are 11 questions. Part 1A is administered by the rater and is one question that focuses on time spent with on- dyskinesia. Off-dystonia is NOT considered. Part 1B is a component of the Patient Questionnaire that covers ten questions on the impact of on-dyskinesia on experiences of daily living. Part 2 will focus on off-dystonia and will have a similar structure: 2A section for the rater and three questions (2B) formatted as a questionnaire for the patient/caregiver Part 1A - Instructions for the Rater In 1. 2. 3. 4. 5. 6. 7. administering Part 1A, the examiner should comply with the following guidelines: Mark on the form the primary data source as patient, caregiver, or patient and caregiver in equal proportion. The response to each item should refer to a period encompassing the prior week including the day on which the information is collected. All items must have an integer rating (no half points, no missing scores). In the event that an item does not apply or cannot be rated (e.g., amputees), the item is marked UR for Unable to Rate. The answers should reflect the usual level of dyskinesia and words such as “usually”, “generally”, “most of the time” can be used with patients. For the question that you will administer, there is a text for you to read (Instructions to patients/caregiver). After that statement, you can elaborate and probe based on the target symptoms outlined in the Instructions to rater. You should not READ the RATING OPTIONS to the patient/caregiver, because these are written in medical terminology. From the interview and probing, you will use your medical judgment to arrive at the best response. The first section focuses on the choreic and dystonic forms of on-dyskinesia and does not assess OFF-DYSTONIA (see later). Additionally, the patient must be reminded throughout the assessment that the focus is NOT on parkinsonism itself nor on tremor. If questions 2-11 (Part 1B) have any answers greater than zero, make sure that the item “TIME SPENT WITH ON DYSKINESIA” (Question 1) reflects that dyskinesia occurred over the past week. If questions 13-15 (Part 2B) have any answers greater than zero, make sure that the item “TIME SPENT WITH OFF DYSTONIA” (Question 12) reflects that dystonia occurred over the past week. Part 1A: On-Dyskinesia Read this statement to the patient: I am going to ask you questions about on-dyskinesia, which is a medical term to describe jerking or twisting movements that occur when your medicine is working to control your Parkinsonism. My questions and the questionnaire that you will answer over the next several minutes do not concern tremor, which is a regular back and forth shaking or any part of the slowness or stiffness of Parkinson's disease itself. The topic is the jerking or twisting movements called on-dyskinesia that can be associated with medication treatment of Parkinson's disease. Do not consider spasms occur when your medications are not working or when you do not take your medication for Parkinson's disease. I will ask about those later. Concentrate only on jerking or twisting movements that occur when your medicine is working to control your Parkinson's disease. Primary source of information: Patient Caregiver Patient and Caregiver in Equal Proportion Part 1.A . ON-DYSKINESIA [exclusive of OFF-state dystonia]—rater to complete 1. TIME SPENT WITH ON-DYSKINESIA Instructions to examiner: Determine the hours in the usual waking day when the patient is ON, and then the hours of dyskinesia. Calculate the percentage. If the patient has dyskinesia in the office, you can point them out as a reference to ensure that patients and caregivers understand what they are rating. You may

also use your own acting skills to enact the dyskinetic movements you have seen in the patient before or show them dyskinetic movements typical of other patients. Exclude from this question early morning and nighttime painful dystonia. Instructions to patient [and caregiver]: Over the past week, how many hours do you usually sleep on a daily basis, including nighttime sleep and daytime napping? Alright, if you sleep \_ hrs, you are awake hrs. Out of those awake hours, how many hours in total are your medications working to control your Parkinson's disease (hours on )? During the hours that your medications are working, do you have jerking or twisting movements? Do not count the times when you have tremor, which is a regular back and forth shaking or times when you have painful cramps or spasms when you have not taken medication or when the medications for Parkinson's disease are not working. I will ask about those later. Concentrate only on these types of jerking or twisting movements that occur when your Parkinson's medicine is working.. Add up all the time during the waking day when your medications are working and you have these jerking or twisting movements. How many hours (use this number for your calculation). SCORE \_ 1. Total Hours On: 2. Total Hours of on-Dyskinesia % On-Dyskinesia = ((2/1)\*100) 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: No dyskinesia < 25% of on-time 26-50% of on-time 51-75% of on-time > 75% of on-time Part 1 B: Patient Dyskinesia Questionnaire: This questionnaire will ask you about the effect of movements called "on-dyskinesias" on your usual activities. On-dyskinesias are jerking or twisting movements that occur in patients with Parkinson's disease when their medicines are working. Please answer question about how dyskinesia affect your activities. Do not answer these questions based on how other problem affect your activities. • Do not base your answers on tremor, which is a regular back and forth shaking and part of the Parkinson's disease itself. • Do not base your answers on slowness or stiffness that is part of Parkinson's disease itself • Do not base your answers on spasms or cramps that can be painful and occur when your medicines are not working. You will answer questions about this problem later. • Concentrate only on jerking or twisting movements when your Parkinson's medicine is working. There are 10 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 the average or usual impact of on-dyskinesia over the past week including today. Only one answer is allowed for each question, so please mark the answer that best describes how on-dyskinesia, if present, affects these activities most of the time. 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 2. SPEECH: Over the past week, when your Parkinson's disease medications were SCORE working, did jerking or twisting movements called on-dyskinesias usually cause problems with your speech? Consider only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all, no problems. \_ Dyskinesias were present, but they did not interfere with my speech. Dyskinesias caused a few problems with my speech and people asked me to repeat myself occasionally. Dyskinesias caused enough problems that I tried to avoid talking when I had on-dyskinesias. When I had dyskinesias, most or all of my speech could not be understood. 3. CHEWING AND SWALLOWING: Over the past week, when your Parkinson's disease medications were working, did jerking or twisting movements called on-dyskinesias SCORE usually cause problems swallowing pills or eating meals? Did you need your pills cut or crushed or your meals to be made soft, chopped or blended to avoid choking? Consider only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: 3: Moderate. 4: Severe: Not at all, no problems. \_ Dyskinesias were present, but they did not interfere with my chewing or swallowing. Dyskinesias caused a few problems with chewing and swallowing and it took me longer to chew or swallow because of on-dyskinesias. Dyskinesias caused enough problems that I tried to avoid chewing and swallowing when I had on-dyskinesias. When I had dyskinesias, I was unable to chew or swallow at all. 4. EATING TASKS: Over the past week, when your Parkinson's disease medications were working, did

jerking or twisting movements called on-dyskinesias usually cause troubles handling your food and using eating utensils? For example, did you have trouble SCORE handling finger foods or using forks, knives, spoons, chopsticks? Consider only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all, no problems. Dyskinesias were present, but they did not interfere with my eating . Dyskinesias caused a few problems with eating and it took me longer to eat because of on-dyskinesias. Dyskinesias caused enough problems that I tried to avoid eating when I had on- dyskinesias. When I had dyskinesias, I needed help for most or all eating tasks. 5. DRESSING: Over the past week, when your Parkinson's disease medications were SCORE working, did jerking or twisting movements called on-dyskinesias usually cause problems with your dressing? For example, did you need help with buttoning, using zippers, putting on or taking off your clothes or jewelry? Consider only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all, no problems. Dyskinesias were present but they did not interfere with dressing tasks. Dyskinesias caused a few problems with dressing and it took me longer to get dressed because of on-dyskinesias. Dyskinesias caused enough problems that I tried to avoid getting dressed when I had on-dyskinesias. When I had dyskinesias, I needed help for most or all dressing tasks. 6. HYGIENE: Over the past week, when your Parkinson's disease medications were working, did jerking or twisting movements called on-dyskinesias usually cause problems SCORE with your personal hygiene? For example, did you need help with washing, bathing, shaving, brushing teeth, or combing your hair? Consider only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all, no problems. Dyskinesias were present but they did not interfere with hygiene tasks. Dyskinesias caused a few problems with hygiene tasks and it took me longer to do these activities because of on-dyskinesias. Dyskinesias caused enough problems that I tried to avoid doing hygiene tasks when I had on-dyskinesias. When I had dyskinesias, I needed help for most or all of my hygiene tasks. 7. HANDWRITING: Over the past week, when your Parkinson's disease medications were SCORE working, did jerking or twisting movements called on-dyskinesias usually cause trouble with your handwriting. Consider only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all, no problems. Dyskinesias were present, but they did not interfere with my handwriting. Dyskinesias caused a few problems with writing and it took me longer to write because of on-dyskinesias. Dyskinesias caused enough problems that I tried to avoid writing when I had on- dyskinesias. When I had dyskinesias, most or all words could not be read. 8. DOING HOBBIES AND OTHER ACTIVITIES: Over the past week, when your Parkinson's SCORE disease medications were working, did jerking or twisting movements called on- dyskinesias usually cause trouble doing your hobbies or other things that you like to do? Consider only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: Not at all, no problems. Dyskinesias were present but they did not interfere with these activities. Dyskinesias caused a few problems with these activities and it took me longer to do them because of on-dyskinesias. 3: Moderate: Dyskinesias caused enough problems that I tried to avoid doing hobbies or other activities when I had on-dyskinesias. 4: Severe: When I had dyskinesias, I was unable to do most or all of these activities. 9. WALKING AND BALANCE: Over the past week, when your Parkinson's disease SCORE medications were working, did jerking or twisting movements called on-dyskinesias usually cause problems with balance and walking. Consider only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all, no problems. Dyskinesias were present but they did not interfere with walking or balance. Dyskinesias caused a few problems with walking. It took me longer to walk because of on-dyskinesias and I occasionally bumped into things. Dyskinesias caused enough problems that I usually used a walking aid (cane, walker) to walk safely without falling. However, I did not usually need the support of another person. I tried to avoid walking when I had on-dyskinesias. When I had dyskinesias, I could not walk safely without falling. 10. PUBLIC AND SOCIAL SETTINGS: Over the past week, when your Parkinson's disease Score medications were working, did jerking or twisting movements called on-dyskinesias usually cause problems when you were dealing with other people or in public? Consider

only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all, no problem. Dyskinesias were present but they did not interfere with these activities. Dyskinesias caused a few problems and I was self-conscious in public but I did not avoid social situations. Dyskinesias caused enough problems that I tried to avoid some social situations when I had on-dyskinesias. When I had dyskinesias, I could not be with people, even friends or family. 11. EXCITING OR EMOTIONAL SETTINGS: Over the past week, when your Parkinson's Score disease medications were working, did jerking or twisting movements called on- dyskinesias usually cause problems during emotional conversations, exciting movies, or other highly stimulating situations. Consider only effects of dyskinesias, not problems caused by Parkinson's disease. 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all, no problem. Dyskinesias were present, but they did not interfere with these activities. Dyskinesias caused few problems. Dyskinesias caused enough problems that I tried to avoid some exciting situations when I had on-dyskinesias. When I had dyskinesias, I could not stay in exciting situations. If questions 2-11 (Part 1B) have any answers greater than zero, make sure that the item "TIME SPENT WITH ON DYSKINESIA" (Question 1) reflects that dyskinesia occurred over the past week. Part 2: Off-Dystonia Ratings: Overview: This portion of the scale assesses the presence and impact of off-dystonia on patients' experiences of daily living. There are four questions. Part 2A is administered by the rater (one question) and focuses on time spent with off- dystonia. Part 2B is a component of the Patient Questionnaire that covers three questions on the impact of painful off- dystonia on experiences of daily living. In administering Part 2A, the examiner should comply with the following guidelines: 1. The responses should refer to a period encompassing the prior week including the day on which the information is collected. 2. The response must be an integer rating (no half points, no missing scores). In the event that the question does not apply or cannot be rated (e.g., amputees), the item is marked UR for Unable to Rate. 3. The answers should reflect the usual level of off-dystonia when present and words such as "usually", "generally", "most of the time" can be used with patients. 4. For the single question that you will administer, there is a text for you to read (Instructions to patients/caregiver). After that statement, you can elaborate and probe based on the target symptoms outlined in the Instructions to rater. You should not READ the RATING OPTIONS to the patient/caregiver, because these are written in medical terminology. From the interview and probing, you will use your medical judgment to arrive at the best response. 5. This section focuses on dystonia during the off-period and this covers dystonia in the early morning or nighttime when patients often have not taken medication or during the day at the end of a dose cycle when they are parkinsonian. The patient must be reminded throughout the assessment that the focus is on off-dystonia and not on parkinsonism itself, tremor, or the on-dyskinesia already covered. Part 2 A: OFF-Dystonia completed by rater. Read this statement to the patient: I am going to ask you questions about another type of movement, called off-dystonia. I am interested in spasms or cramps that occur when the Parkinson's disease medications are not taken or are not working well. We call that time period OFF. Off-dystonia is sometimes painful and often occurs in the early morning or nighttime, but occasionally at other times as well when your Parkinson's disease medications are not working. The feet and toes can be affected or other body areas My question and the questionnaire that you will answer over the next few minutes do not concern tremor, which is a regular back and forth shaking. Also, the questions are not about the slowness or stiffness of Parkinson's disease itself. Finally, they also do not concern the jerking or twisting movements called dyskinesia already covered. For these questions, please concentrate only on the spasms or cramps that we call OFF-Dystonia (completed by rater) 12. TIME SPENT WITH OFF-DYSTONIA Over the past week, on a typical day, think about the number of hours of the day when you are stiff and slow, whether this is before you take morning medications, perhaps late in the evening, or during the day when the good effects of medication have worn out. Within these "OFF" times, how many hours or minutes do you have spasms or cramps that we call OFF-dystonia? SCORE 0 = 1 = 2 = 3 = 4 = Never Less than 30 minutes a day Less than 60 minutes a day. Less than 2 hours a day. Greater than 2 hours a day. Questionnaire for Patient Part 2 B : Patient Questionnaire: Instructions: This

questionnaire asks you questions about spasms or cramps that occur when Parkinson's disease medications are not taken or when they are not working well. We call that time OFF. Off-dystonia movements are sometimes painful and often occur in the early morning or nighttime, but occasionally at other times when your Parkinson's disease medications are not working. Do not answer these questions based on how other problem affect your activities. • Do not base your answers on tremor, which is a regular back and forth shaking and part of the Parkinson's disease itself. • Do not base your answers on slowness or stiffness that is part of Parkinson's disease itself. • Do not base your answers on jerking, twisting movements that you have already rated. • Concentrate only on spasms or cramps, called off-dystonia. In general, these movements develop in the early morning, nighttime or when the good effects of medicines have worn off. Sometimes, there is pain along with the spasms. There are 3 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 the average or usual impact of off-dystonia over the past week including today. Only one answer is allowed for each question, so please mark the answer that best describes what you can do most of the time. 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 13. EFFECTS OF SPASMS OR CRAMPS CALLED OFF-DYSTONIA SEPARATE FROM PAIN ON ACTIVITIES. During the past week, separate from pain, have spasms or cramps called off- SCORE dystonia occurred? 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all. \_ Off-dystonia occurred but it did not interfere with my daily activities. Off-dystonia caused a few problems and it took me longer to do activities because of off-dystonia. Off-dystonia caused enough problems that I avoided doing these activities when I had off-dystonia. When off-dystonia occurred, I could not do many activities. 14. EFFECTS OF PAIN FROM OFF-DYSTONIA ON DAILY ACTIVITIES: On average during this past week, if spasms or cramps called off-dystonia occurred, did pain limit your activities? SCORE 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not at all, no pain from off-dystonia. \_ I had pain from off-dystonia, but it did not limit my activities Pain from off-dystonia caused a few problems and it took me longer to do activities because of pain from off-dystonia. Pain from off-dystonia caused enough problems that I avoided doing these activities when I had pain from off-dystonia. Because of pain from dystonia, I could not do many activities. 15. DYSTONIA PAIN: On average during the past week, how severe was the pain from the spasms or cramps of off-dystonia? SCORE 0: Normal: 1: Slight: 2: Mild: 3: Moderate: 4: Severe: Not painful \_ Mild ache or discomfort. Moderate ache and discomfort. Severe discomfort. Excruciating pain. If questions 13-15 (Part 2B) have any answers greater than zero, make sure that the Item "TIME SPENT WITH OFF DYSTONIA" (Question 12) reflects that dystonia occurred over the past week. Part 3. OBJECTIVE EVALUATION OF DYSKINESIA DYSABILITY Instructions for the rater: In this section, you will observe the patient or observe a videotape of the patient during four activities of daily living. • You will rate IMPAIRMENT by scoring the global intensity of the dyskinesia (giving an overall rating by body part that includes both choreic dyskinesia and dystonia) during each task. • You will rate DISABILITY by scoring the functional impact of dyskinesia on each of the tasks. • You will then account for the different types of dyskinesia you observed and judge the most prominent form of dyskinesia. • The final IMPAIRMENT score for each body part will be HIGHEST score seen in that body part during the four tasks. Use the data sheet to enter the highest score. • The DISABILITY score is entered for each of the four tasks. • During the evaluations, ignore deficits caused by parkinsonism. Instructions on conducting the examination or videotape. Communication: Instruct subject to look at evaluator (or camera) and describe a picture (recommended Cookie Thief Drawing, but others can be used). Evaluate interference with communication as judged by ability to maintain eye contact, cadence and pronunciation of words and distraction of subject and listener caused by movements. Ignore dysarthria caused by parkinsonism. Drinking from a cup: Instruct the subject to pick up a 4 oz cup filled to within 1 cm of brim with water with the dominant hand and bringing it to lips, drink contents

and replace cup on table. Ignore bradykinesia or tremor from parkinsonism. Dressing: Instruct the subject to put on a lab coat and do up three buttons, undo the buttons and take the coat off. [Allow up to 60 seconds]. Ignore bradykinesia or tremor from parkinsonism. Ambulation: Instruct the patient to rise from a chair, walk 15 feet, return and sit back down in the chair. Ignore tremor or bradykinesia from parkinsonism. Rush filming protocol INTENSITY SCALE: IMPAIRMENT (PART 3) 0=No dyskinesia 1=Questionable or mild dyskinesia 2=Moderate dyskinesia with movements which are not intrusive nor distort voluntary movements 3=Severe dyskinesia which disturbs but does not prohibit posture or voluntary movements 4=Incapacitating dyskinesia which prohibits some postures and voluntary movements IMPAIRMENT SCORE FACE Highest score NECK R ARM/SHOULDER L ARM/SHOULDER TRUNK R LEG/HIP L LEG/HIP (16) (17) (18) (19) (20) (21) (22) DISABILITY SCALE (PART 4) Communication 0=No dyskinesia Communication Drinking Dressing Ambulation 1=Dyskinesia present but does not impair communication 2=Dyskinesia impairs communication but patient is fully understandable 3=Dyskinesia interferes with communication such that parts of communication cannot be understood but overall content is understandable 4=Dyskinesia interferes with comprehension of overall communication (23) Drinking from a cup 0=No dyskinesia observed 1=Dyskinesia present but it does not affect performance of the task 2=Dyskinesia affect the smooth performance but causes no splashing or spilling 3=Dyskinesia affects performance such that patient spills a few drops of water 4=Dyskinesia affects performance such that patient spills more than a few drops or dyskinesia causes coughing or choking. (24) Dressing 0=No dyskinesia observed 1=Dyskinesia present but does not interfere with or slow dressing 2=Dyskinesia affects smooth performance of task but the performance is at most minimally slowed 3=Dyskinesia interferes and slows performance but it is completed within 60 seconds 4=Dyskinesia precludes completing the task within 60 seconds (25) Ambulation 0=No dyskinesia observed 1=Mild dyskinesia present but does not alter normal synchrony or cadence 2=Dyskinesia is present which alters the normal cadence of rising, sitting or walking but does not slow overall performance. 3=Dyskinesia is present which disrupts or distorts arising, sitting or walking. Performance is slowed. Patient is able to rise and walk without imminent danger of falling. 4=Dyskinesia prohibits walking safely without assistance (26) Considering all of the activities above: Patient exhibits: (check all applicable answers) \_On dyskinesia \_Off dystonia Transition state (neither clearly On or Off What movements were seen? (check all types) chorea \_dystonia \_Other The predominant dyskinesia was (check one) chorea \_dystonia \_Other \_\_\_ No dyskinesia or dystonia Score summary Historical Score Objective Score 1. Time dyskinesia 16. Face 2. Speech 17. Neck 3. Chewing/Swallowing 18. Right Hand/arm/shoulder 4. Eating tasks 19. Left Hand/arm/shoulder 5. Dressing 20. Trunk 6. Hygiene 21. Right foot/leg/hip 7. Handwriting 22. Left foot/leg/hip 8. Doing hobbies/activities 23. Communication 9. Walking/balance 24. Drinking 10. Public/social 25. Dressing 11 Exciting situations 26. Ambulation 12 Time Off dystonia 13. Dystonia effects on activities (not pain) 14. Effect of Pain from dystonia 15. Dystonia pain severity Historical sub-score (sum) Objective sub-score (sum) Total UDysRS score (Historical + Objective): [http://www.movementdisorders.org/MDS-Files1/PDFs/MDS-UPDRS-Rating-Scales/UDysRS\\_English\\_modified\\_2AUG2013.pdf](http://www.movementdisorders.org/MDS-Files1/PDFs/MDS-UPDRS-Rating-Scales/UDysRS_English_modified_2AUG2013.pdf)

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