

APPENDIX E2 DISEASE PROGRESSION

Form Approved
OMB No. 0923-0041
Exp. Date 01/31/2023

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The following rating scale is used to assess changes in physical functioning in persons with ALS and other motor neuron diseases.

Self-Administered Rating Scale (to be completed 3 times in the first year and every 6 months thereafter)

The questions refer to how you are currently functioning at home. Please read each item carefully and base your answers on your functioning today compared to the time before you had any symptoms of ALS or another motor neuron disease. Please choose the answer that best fits your functional status today.

Compared with the time before you had symptoms of ALS or another motor neuron disease:

CODES	DESCRIPTION
S7_Q01	1. Have you noticed any changes in your speech? 0 No change 1 I have a noticeable speech difference. 2 My speech has changed. I am asked often to repeat words or phrases. 3 My speech has changed. I sometimes need the use of alternative communication methods (i.e. computer, writing pad, letter board or eye chart). 4 I am unable to communicate verbally.
S7_Q02	2. Have you noticed any changes (increases) in the amount of saliva in your mouth (regardless of any medication use)? 0 No change 1 I have slight but definite excess of saliva with or without night time drooling. 2 I have moderate amounts of excessive saliva with or without minimal day time drooling. 3 I have marked amounts of excessive saliva with some daytime drooling. 4 I have marked excessive saliva with marked drooling requiring a constant tissue or handkerchief.
S7_Q03	3. Have there been any changes in your ability to swallow? 0 No changes for all foods and liquids 1 I have some changes in swallowing or occasional choking episodes (including coughing during swallowing). 2 I am unable to eat all consistencies of food and have modified the consistency of foods eaten. 3 I use a feeding tube (PEG) to supplement what is eaten by mouth. 4 I do not eat anything by mouth and receive all nutrition through a feeding tube (PEG).
S7_Q04	4. Has your handwriting changed? Please choose the best answer that describes your handwriting with your dominant (usual) hand without a cuff or brace. 0 No changes 1 My handwriting is slower and/or sloppier but all the words are legible. 2 Not all my words are legible. 3 I am able to hold a pen but unable to write.

4 I am unable to hold a pen.

The following question refers to your ability to cut foods and handle utensils (feed yourself). Compared with the time before you had symptoms of ALS or another motor neuron disease:

CODES	DESCRIPTION
S7_Q05	5. How do you get most of your nutrition? 1 Eat most of my meals by mouth 2 Get most of my nutrition through a feeding tube (PEG)
S7_Q06	6. Cutting food and handling utensils: 0 No change 1 My cutting food or handling utensils is somewhat slow and clumsy (or different than before) but I do not need assistance or adaptive equipment. 2 I sometimes need help with cutting more difficult foods. 3 My food must be cut by someone else but I can feed myself slowly without assistance. 4 I need to be fed.
S7_Q07	7. Using a feeding tube (PEG) 0 I use a PEG without assistance or difficulty. 1 I use a PEG without assistance however I may be slow and /or clumsy. 2 I require assistance with closures and fasteners. 3 I provide minimal assistance to a caregiver. 4 I am unable to perform any of the manipulations.
S7_Q08	8. Has your ability to dress and perform self-care activities (i.e. bathing, teeth brushing, shaving, combing your hair, other hygienic activities) changed? 0 No change 1 I perform self-care activities without assistance but with increased effort or decreased efficiency. 2 I require intermittent assistance or use different methods (i.e. sit down to get dressed, fasten buttons with a fastener or your non-dominant hand). 3 I require daily assistance. 4 I do not perform self-care activities and am completely dependent on caregiver.
S7_Q09	9. Has your ability to turn in bed and adjust the bed clothes (i.e. cover yourself with the sheet or blanket) changed? 0 No change 1 I can turn in bed and adjust the bed clothes without assistance but it is slower or more clumsy. 2 I can turn in bed or adjust the bed clothes without assistance but with great difficulty. 3 I can initiate turning in bed or adjusting the bed clothes but require assistance to complete the task. 4 I am helpless in bed.

Compared with the time before you had symptoms of ALS or another motor neuron disease:

CODES	DESCRIPTION
S7_Q10	10. Has your ability to walk changed? 0 No change 1 My walking has changed but I do not require any assistance or devices (i.e. foot brace, cane, or

- walker).
- 2 I require assistance to walk (i.e. cane, walker, foot brace or hand held assistance).
 - 3 I can move my legs or stand up but am unable to walk from room to room.
 - 4 I cannot walk or move my legs.
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CODES DESCRIPTION

S7_Q11 11. Has your ability to climb stairs changed?

- 0 No change
 - 1 I am slower.
 - 2 I am unsteady and/or more fatigued.
 - 3 I require assistance (i.e. using the handrail, cane or person).
 - 4 I cannot climb stairs.
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S7_Q12 12. Do you experience shortness of breath or have difficulty breathing?

- 0 No change
 - 1 I have shortness of breath only with walking.
 - 2 I have shortness of breath with minimal exertion (i.e. talking, eating, bathing or dressing).
 - 3 I have shortness of breath at rest while either sitting or lying down.
 - 4 I have significant shortness of breath (all of the time) and considering using mechanical ventilation.
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S7_Q13 13. Do you experience shortness of breath or have difficulty breathing while lying down on your back?

- 0 No change
 - 1 I occasionally have shortness of breath while lying on back but don't routinely use more than two (2) pillows to sleep.
 - 2 I have shortness of breath while lying on back and require more than two pillows (or an equivalent) to sleep.
 - 3 I can only sleep sitting up due to shortness of breath.
 - 4 I require the use of respiratory (breathing) support (BiPAP® or invasive ventilation via tracheostomy) to sleep and do not sleep without it.
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S7_Q14 14. Do you require respiratory (breathing) support?

- 0 I need no respiratory support.
 - 1 I need intermittent use of BiPAP®.
 - 2 I need continuous use of BiPAP® at night.
 - 3 I need continuous use of BiPAP® at night and during the day (nearly 24 hours per day).
 - 4 I need mechanical ventilation by intubation or tracheostomy.
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S7_Q15 15. Please indicate who completed this survey:

- 1 I completed the survey (patient).
 - 2 I completed the survey with assistance.
 - 3 I completed the survey with assistance from caregiver or family member.
 - 4 The caregiver completed the survey alone.
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S7_Q16 16. What is your current weight? ___ ___ ___ lbs. ENTER:

S7_Q17 17. Have you been hospitalized in the past 6 months?

- 1 Yes
GO TO: S7_Q18
- 2 No

S7_Q18 18. If yes, how many times were you in the hospital? ENTER: ___ number of times.

S7_Q19 19. How many days were you hospitalized? ENTER: ___ total number of days

S7_Q20 20. Have you gone to the Emergency Room in the past 6 months?

1 Yes

GO TO: S7_Q21

2 No

S7_Q21 21. If yes, how many times have you visited the Emergency Room? ENTER: ___ number of times