

Today's Date: (day/month/year) ___ / ___ / _____

How did you complete this survey?
Please check one box

- In clinic using a paper form
- At home using a paper form
- In clinic using a computer or tablet
- At home using a computer or tablet
- At home by telephone (administered by clinic staff)

Who is completing the survey?
Please check one box

- Patient
- Patient via Caregiver

What diagnosis did your doctor tell you that you have?

- ALS (Amyotrophic Lateral Sclerosis)
- PLS (Primary Lateral Sclerosis)
- PMA (Progressive Muscular Atrophy)
- I do not know my diagnosis
- Other (please enter):

Would you be willing to be contacted about opportunities to take part in our ALS Specialty Clinics medical research? We are not keeping your name at this time, we are just asking the number of possible future participants.

- Yes! Please count me in!
- No, I'm not able to at this time
- Please ask me about a specific research project, and then I'll decide

When were you given your diagnosis, if known? (month and year)

___ / _____

When did your symptoms / weakness start? (month and year; we understand that this might be a "best guess" or estimate)

___ / _____

In what region(s) of your body did the **first** symptoms of ALS begin? (please be as specific as possible)

Area	Right Side	Left Side
Hand	<input type="checkbox"/>	<input type="checkbox"/>
Foot	<input type="checkbox"/>	<input type="checkbox"/>
Arm	<input type="checkbox"/>	<input type="checkbox"/>
Leg	<input type="checkbox"/>	<input type="checkbox"/>
Swallowing <input type="checkbox"/>		
Speech <input type="checkbox"/>		
Breathing <input type="checkbox"/>		
Other? (please write in): _____		

DIRECTIONS for the following questions:

Please think about how you are doing on an average day over the past month or so (and this includes your routine use of therapies, devices, medications, etc.) when answering these questions.

1. Speech

- 4 Normal speech processes
- 3 Detectable speech with disturbances
- 2 Intelligible with repeating
- 1 Speech combined with non-vocal communication
- 0 Loss of useful speech

2. Salivation

- 4 Normal
- 3 Slight, but definite excess of saliva in mouth; may have nighttime drooling
- 2 Moderately excessive saliva; may have minimal drooling
- 1 Marked excess of saliva with some drooling
- 0 Marked drooling; requires constant tissue or handkerchief

3. Swallowing

- 4 Normal eating habits
- 3 Early eating problems – occasional choking
- 2 Dietary consistency changes
- 1 Needs supplemental tube feeding
- 0 Feeding tube only

4. Handwriting (with the hand you normally write with)

- 4 Normal
- 3 Slow or sloppy; all words are legible
- 2 Not all words are legible
- 1 Able to grip pen but unable to write
- 0 Unable to grip pen

5. Please answer question 5a if you do not have a feeding tube or if you require the use of a feeding tube for 50% or LESS of your nutritional needs.

5a. Cutting food and handling utensils

- 4 Normal
- 3 Somewhat slow and clumsy, but no help needed
- 2 Can cut most foods, although clumsy and slow; some help needed
- 1 Food must be cut by someone, but can still feed slowly
- 0 Needs to be fed

Please answer question 5b if you always use a feeding tube OR if you have a feeding tube and use it MORE than 50% of the time for your nutritional needs.

5b. Cutting food and/or handling feeding tube closures, cans or utensils

- 4 Normal
- 3 Clumsy, but able to perform all manipulations independently
- 2 Some help needed with closures and fasteners
- 1 Provides minimal assistance to caregivers
- 0 Unable to perform any aspect of task

6. Dressing and hygiene

- 4 Normal function
- 3 Independent and complete self-care with effort or decreased efficiency
- 2 Intermittent assistance or substitute methods (can include zipper pulls, button fasteners, sitting instead of standing)
- 1 Need attendant for self-care
- 0 Total dependence

7. Turning in bed and adjusting sheets

- 4 Normal
- 3 Somewhat slow and clumsy, but no help needed
- 2 Can turn alone or adjust sheets, but with great difficulty
- 1 Can initiate, but not turn or adjust sheets alone
- 0 Helpless

8. Walking

- 4 Normal
- 3 Early ambulation difficulties
- 2 Walks with assistance (includes holding on to someone's arm)
- 1 Non-ambulatory functional movement only
- 0 No purposeful leg movement

9. Climbing stairs

- 4 Normal
- 3 Slow
- 2 Mild unsteadiness or fatigue
- 1 Needs assistance
- 0 Cannot do

10. Shortness of breath (Dyspnea)

- 4 None
- 3 Occurs when walking
- 2 Occurs with one or more of the following: eating, bathing, dressing
- 1 Occurs at rest, difficulty breathing when either sitting or lying
- 0 Significant difficulty, considering using mechanical respiratory support

11. Trouble breathing while lying down (Orthopnea)

- 4 None
- 3 Some difficulty sleeping at night due to shortness of breath; does not routinely use extra pillow(s)
- 2 Need extra pillow(s) in order to sleep (at least one pillow more than usual)
- 1 Can only sleep sitting up
- 0 Unable to sleep

12. Breathing Assistance/Respiratory Insufficiency (Note: A BiPAP is a machine that changes the pressure as per the breathing pattern; a CPAP is a machine that delivers air pressure at a single level. Both machines make it easier to breathe.)

- 4 None
- 3 Intermittent use of BiPAP or CPAP
- 2 Continuous use of BiPAP or CPAP during the night
- 1 Continuous use of BiPAP or CPAP during the night and day
- 0 Invasive mechanical ventilation by intubation or tracheostomy or noninvasive mechanical ventilation

13. Pain

- 4 No pain
- 3 Some pain, but does not limit my activities
- 2 Pain that minimally limits my activities
- 1 Pain that moderately limits my activities
- 0 Severe pain that limits what I can do

14. Crying or laughing uncontrollably

- 4 No problems
- 3 Sometimes, but it doesn't interfere with my daily activities
- 2 Yes, and this causes some minor limits on my activities outside of my home
- 1 Yes, and this moderately limits my activities outside of my home
- 0 Yes and I am unable to control it and it severely limits my activities outside of my home

15. For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life's ups and downs; is this true for you?

- 4 This is very true for me
- 3 This is usually true for me
- 2 It depends – sometimes this is true and sometimes not
- 1 This is usually not true for me
- 0 This is not at all true for me

16. In addition to brand new experimental treatments for ALS, it is also important that we study how to best use currently available treatments. Which of the following clinical research questions would you be interested in knowing the answer to? (check all that apply)

- Is there a benefit to combining drug therapies in ALS? (For example, testing if combining two currently available drugs with riluzole benefits patients)
- Are there vitamin combinations/herbal supplements which can slow down ALS?
- Does starting BiPAP earlier provide any benefit in ALS?
- Do special diets have any role in treatment of ALS?
- What is the best way to treat throat spasms that lead to choking or coughing?
- Do you have an idea for research that you would like to share? Please write in below

17. Is there something you'd like to share that we have not asked about? Please use this space to tell us! Please do not enter any information in this area that we would be able to identify you. This includes name, date of birth, location.

THANK YOU VERY MUCH FOR COMPLETING THE SURVEY!

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