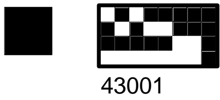

43001

# PATIENT FORM

## ALS PATIENT CARE DATABASE

**This survey asks for your views about your health. This information will help your doctor to better care for you. Answer each question by checking the appropriate box. This is not a test. There are no right or wrong answers. If you are unsure how to answer any question, please give the best answer you can.**

| *Please use a blue or black pen to complete the survey.* | *Please print neatly within the boxes as shown:* 1 2 3 4 5 6 7 8 9 0 | *Please shade circles completely as shown:* *Correct:* ● *Incorrect:* ⊠ ✓ |
|---|---|---|

**Questions 1-6 should be filled out by the doctor or clinic staff**

**1. Patient ID**

**2. Clinic/Site ID**

**3. Physician ID**

**4. Today's date (month/day/year)**

__ __ / __ __ / 2 0 0 __

**5. Is this the first time this form has been completed by this patient?**

O Yes O No

If No, have patient begin at question 20

**6. Patient height**

(Complete once - first time patient fills out this form)

__ feet __ __ inches O not done

**Demographic Information. Questions 7-19: Only answer if this is the 1st time you have filled out this form**

**7. Date of birth (month/day/year)**

__ __ / __ __ / __ __ __ __

**8. Place of birth**

City ______________________

State/Province Zip Code

**9. Patient initials**

**10. Are you**

O Male O Female

**11. Which of the following best describes your racial background?**

O White/Caucasian
O Oriental/Asian, Pacific Islander
O North American Indian, Eskimo/Aleutian
O Black/African American
O Other
O Prefer not to answer

**12. Are you of Spanish or Hispanic origin or ancestry?**

O Yes O No O Prefer not to answer

**13. Are you a veteran of the military?**

O No O USA O Canada O Other

**13a. Years of Service**

from __ __ __ __ to __ __ __ __

**13b. What is the highest grade you completed in school?**

O Any postgraduate work
O College graduate
O Some college
O High School graduate
O Some high school
O 8th grade or less

**ALS Information. Questions 14-19: Only answer if this is the 1st time you have filled out this form**

**14. What was your first ALS symptom? (Check ONE)**

O Twitching or cramping of muscles
O Impaired use of arms or legs
O Weakness
O Fatigue
O Weight loss
O "Thick" speech & difficulty projecting voice
O Swallowing problems
O Breathing problems
O Other ______________________

**15. What symptom(s) of ALS brought you to the doctor? (check all that apply)**

O Twitching or cramping of muscles
O Impaired use of arms and/or legs
O Weakness
O Fatigue
O Weight loss
O "Thick" speech & difficulty projecting voice
O Swallowing problems
O Breathing problems
O Other ______________________



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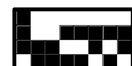

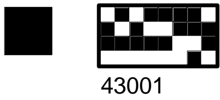

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# PATIENT FORM

ALS PATIENT CARE DATABASE

**16. What was your first diagnosis? (Check ONE)**

- O ALS
- O Other motor neuron disease
- O Pinched nerve - neck
- O Pinched nerve - back
- O Arthritis
- O Carpal tunnel syndrome
- O Muscle disease
- O Neuropathy
- O Psychiatric diagnosis
- O Stroke
- O Other
- O Don't know

**17. Was a second opinion obtained?**

- O No
- O Yes, at my request
- O Yes, at my doctor's request

**The following questions relate to the first interview at which you were given the diagnosis that you definitely had ALS.**

**18. Which physician was the first to give you the diagnosis that you definitely had ALS? (check one)**

- O Primary Care Physician
- O Community Neurologist
- O Neurologist at an ALS clinic
- O Other ____________________

**18a. Did the physician who first gave you the diagnosis do so (check one):**

- O In person
- O By letter
- O By telephone
- O Other ____________________

**19. Were the people who are important to you present at the time you were given the diagnosis?**

O Yes O No

**19a. If not, was a follow-up communication arranged?**

O Yes O No

**19b. At the time you were given the diagnosis of ALS, were you given information about**

a. the disease O Yes O No

b. organizations providing resources for the ALS patient (e.g. ALSA/MDA, etc.)? O Yes O No

**19c. Were you satisfied with the way the diagnosis was given to you? (Check all that apply)**

- O Satisfied
- O Too little information
- O No sense of hope given
- O Insensitive delivery
- O Didn't understand what was being said

## Symptomatic Management

**Please answer these questions each time you complete this form.**

**20. If you have excess salivation or drooling, were you offered medication?**

O Yes O No O Do not have symptom

**20a. If yes, please check which medication you have taken or are currently taking for excess salivation or drooling. (Check all that apply)**

| | Have not tried | Tried and helpful | Tried and not helpful |
|---|---|---|---|
| Amitriptyline (Elavil) | O | O | O |
| Glycopyrrolate (Robinul) | O | O | O |
| Atropine | O | O | O |
| Scopolamine (Transderm patch) | O | O | O |
| Botox iniections | O | O | O |
| Other ____________________ | O | O | O |

**20b. If you have excessive laughter or crying, were you offered medication?**

O Yes O No O Do not have symptom

**20c. If yes, please check which medication you have taken or are currently taking for excessive laughter or crying (Check all that apply).**

| | Have not tried | Tried and helpful | Tried and not helpful |
|---|---|---|---|
| Elavil | O | O | O |
| Luvox | O | O | O |
| Paxil | O | O | O |
| Prozac | O | O | O |
| Other ______________ | O | O | O |

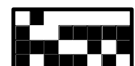
## Personal Information

**Please answer these questions each time you complete this form.**

**21. Which of the following categories best describes your household's total income before taxes last year? Please include income from all sources such as salaries and wages, Social Security, retirement income, investments, disability insurance, and other sources.**

- O Less than $20,000
- O $20,000 - $39,999
- O $40,000 - $59,999
- O $60,000 - $79,999
- O $80,000 - $99,999
- O $100,000 or more





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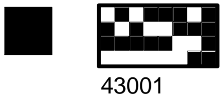

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# PATIENT FORM

ALS PATIENT CARE DATABASE

**22. What type of health insurance do you have? (Check all that apply.)**

- O Medicare
- O Medicaid
- O Commercial insurance
- O Health Maintenance Org. (HMO)
- O Canadian Provincial Insurance
- O Veterans' Affairs
- O Other ___________
- O Unknown
- O None

**22a. Other sources of health coverage or financial support you receive (check all that apply):**

- O None
- O An MDA clinic
- O Other source
- O An ALSA Clinic
- O The clinic that provides your care

**23. In providing authorization and reimbursement for care needed for ALS symptoms and diagnosis, my HMO/insurance company has been**

- O Very helpful
- O Somewhat helpful
- O Unhelpful
- O Does not apply

**24. Which of the following categories best describes your out-of-pocket expenses for your ALS care to date?**

- O Less than $5,000
- O $10,000 - $29,999
- O $5,000 - $9,999
- O $30,000 or more

**25. Which of the following best describes your current marital status?**

- O Now Married
- O Divorced
- O Widowed
- O Never married
- O Separated

**26. Do you live:**

- O Alone
- O With friend
- O With spouse
- O With other person
- O With other relative
- O With unmarried partner

**26a. Current Zip Code:** [ ][ ][ ][ ][ ][ ]

**27. Employment status: Are you presently working?**

- O Full-time
- O Part-time
- O No

Date last worked (month/day/year)

[ ][ ] / [ ][ ] / [ ][ ][ ][ ]

**27a. If not working, have you filed for disability?**

O Yes O No

If Yes: Date disability claim filed (month/day/year)

[ ][ ] / [ ][ ] / [ ][ ][ ][ ]

Date disability started (month/day/year)

[ ][ ] / [ ][ ] / [ ][ ][ ][ ]

## Self-Reported Activities of Daily Living Status

**Please answer these questions each time you complete this form.**

**28. How do you accomplish your activities of daily living? (Check only ONE box across each row.)**

% of Activities of Daily Living

| | less than 10% | 10-50% | 51-90% | more than 90% |
|---|---|---|---|---|
| Self | O | O | O | O |
| Spouse | O | O | O | O |
| Paid attendant | O | O | O | O |
| Other | O | O | O | O |

**29. Have you taken any medications for any of the following symptoms of ALS to date (at enrollment visit) or since the last ALS form was completed (at follow-up visits?)**

| | Don't have symptoms | No Meds offered | Med taken helpful | Med taken not helpful |
|---|---|---|---|---|
| a. Cramps (such as quinine, Dilantin, Valium, Baclofen) | O | O | O | O |
| b. Spasticity or stiffness (such as Baclofen, Valium, antrolene) | O | O | O | O |
| c. Sleep disturbance (such as Elavil, Valium) | O | O | O | O |
| d. Depression (such as Elavil, Prozac, Zoloft) | O | O | O | O |
| e. Constipation | O | O | O | O |
| f. Other ___________ | O | O | O | O |

**30. Are you currently taking Rilutek (Riluzole) for treatment of ALS?**

O Yes O No

**30a. If no, why not? (Check all that apply)**

- O Never heard of it
- O My doctor discouraged me from taking it
- O Too expensive or not covered by insurance
- O I don't believe that it is beneficial
- O Concern about potential side effects
- O I tried it, but decided to stop due to side effects
- O Other ______________________________



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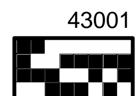

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**30b. Have you used alternative therapies such as vitamins or food supplements to date (if this is the first time you have filled out this form) or since you last completed one of these forms (at follow-up visits)?**

O Yes O No

**31. Please check the box corresponding with any alternative therapies you currently use and record the daily dose you take when indicated? (check all that apply)**

Daily dose

O None
O Multivitamins
O Food supplements
O Other ______
O Vitamin B ______
O Vitamin C ______
O Vitamin E ______

**31a. Approximately, what is the cost of all alternative treatments and complimentary medications that you use per month. Do not include the cost of drugs prescribed by your doctor in your answer.**

Cost per month $ [ ] , [ ][ ][ ]

**31b. Have you used any of the following therapies to date (at enrollment visit) or since the last ALS form was completed (at follow-up visits)?**

| | Have not tried | Tried and helpful | Tried and not helpful |
|---|---|---|---|
| Occupational therapy | O | O | O |
| Physical therapy (PT) | O | O | O |
| Speech therapy | O | O | O |
| Dietary (Nutrition) | O | O | O |
| Social work | O | O | O |
| Psychology/psychiatry | O | O | O |
| Home nurse | O | O | O |
| Other ______ | O | O | O |

**31c. Have you been admitted to a nursing home or hospice program to date (at enrollment visit) or since the last ALS form was completed (at follow-up visits)?**

O Yes, nursing home

O Yes, home hospice

O Yes, residential hospice

O No

## General Health Status

**Please answer these questions each time you complete this form. Questions 32-38 are from the SF-12 Health Survey V2.0,** **copyright 1994 The Health Institute at New England Medical Center. All rights reserved. Reproduced with permission of the Medical Outcomes Trust.**

*This portion of the questionnaire asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Please answer every question by checking only one answer. If you are unsure about how to answer, please give the best answer you can.*

**32. In general, would you say your health is**

O Excellent O Good O Poor
O Very good O Fair

**33. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

a. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.

O Yes, limited a lot O No, not limited at all
O Yes, limited a little

b. Climbing several flights of stairs

O Yes, limited a lot O No, not limited at all
O Yes, limited a little

**34. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

a. Accomplished less than you would like

O All of the time O A little of the time
O Most of the time O None of the time
O Some of the time

b. Were limited in the kind of work or other activities

O All of the time O A little of the time
O Most of the time O None of the time
O Some of the time

**35. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

a. Accomplished less than you would like

O All of the time O A little of the time
O Most of the time O None of the time
O Some of the time

b. Did work or other activities less carefully than usual

O All of the time O A little of the time
O Most of the time O None of the time
O Some of the time


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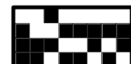
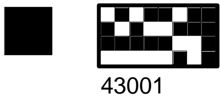




43001

# PATIENT FORM

ALS PATIENT CARE DATABASE

**36. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

- O Not at all
- O Quite a bit
- O A little bit
- O Extremely
- O Moderately

**37. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling.**

a. Have you felt calm and peaceful?

- O All of the time
- O A little of the time
- O Most of the time
- O None of the time
- O Some of the time

**How much of the time during the past 4 weeks**

b. Did you have a lot of energy?

- O All of the time
- O A little of the time
- O Most of the time
- O None of the time
- O Some of the time

c. Have you felt downhearted and blue?

- O All of the time
- O A little of the time
- O Most of the time
- O None of the time
- O Some of the time

**38. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**

- O All of the time
- O A little of the time
- O Most of the time
- O None of the time
- O Some of the time

## NUTRITION / FEEDING TUBE

If you have experienced difficulty swallowing or eating, please answer questions 39-43. Otherwise, go to question 44

**39. When did your difficulty with swallowing first begin (choking, cough with meal, too much time, fatigue from eating)?** [ ][ ] / [ ][ ]
Month Year

**40. Has your physician discussed or recommended a feeding tube?** O Yes O No

a. If Yes, when [ ][ ] / [ ][ ]
Month Year

b. If Yes, to your knowledge, a feeding tube was recommended based on (check all that apply)

- O swallowing difficulty
- O breathing status
- O weight loss
- O test results

c. Specify weight loss [ ][ ][ ] lbs. over [ ][ ] months

current weight [ ][ ][ ] lbs.

weight before ALS [ ][ ][ ] lbs.

**41. Do you have a feeding tube?** O Yes O No

a. Yes, since when? [ ][ ] / [ ][ ]
Month Year

b. If No, what is your reason for not selecting a feeding tube? (Check all that apply)

- O Don't like the idea
- O Not enough information
- O I still think I am eating o.k.
- O Other ______________

**42. Complications of feeding tube: Have you had any problems after the feeding tube procedure? (Check all that apply)**

- O Minor problem
- O Serious problems
- O Constipation, diarrhea
- O Other ______________
- O Required delayed discharge
- O No complications

**43. Has your feeding tube been helpful?** O Yes O No

## RESPIRATION

**44. Are you currently on continuous Non-Invasive Mechanical Ventilation? (e.g., BiPap, CPap)** O Yes O No

**If Yes:**

**44a. Specify the number of hours Non-Invasive Ventilation is used per 24 hour period** [ ][ ]

**If No:**

**44b. Was it offered to you?** O Yes O No
**Did you try it?** O Yes O No
**Did you tolerate it?** O Yes O No

**45. Was continuous Non-Invasive Ventilation therapy (check one)**

- O your choice?
- O the choice of your medical team/physician?
- O a combination of both?

**46. Has this therapy helped you?**

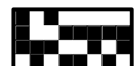
O Yes O No

**If No:**

**47. Is your medical team/physician assisting you in withdrawing the continuous Non-Invasive Ventilation therapy?**

O Yes O No O Have not asked





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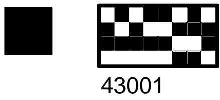

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# PATIENT FORM

ALS PATIENT CARE DATABASE

**48. Are you currently on a ventilator with tracheostomy?**

○ Yes ○ No (skip to question 51)

**If Yes:**

**49. Was the ventilator with tracheostomy (check one)**

○ your choice?
○ the choice of your medical team/physician?
○ a combination of both?

**50. Are you interested in continuing on the ventilator?**

○ Yes ○ No

**If No:**

**50a. Is your medical team/physician assisting you in withdrawing the ventilator?**

○ Yes ○ No ○ Have not asked

**51. Have you received enough information about ALS?**

○ Yes ○ No

**52. How many doctor visits for ALS-related care have you had in the past 12 months?**

☐☐

**53. Have your doctor visits for ALS occurred:**

○ Too seldom ○ Just right ○ Too frequently

**54. In general, are you satisfied with your current medical care for ALS?**

○ Dissatisfied ○ Satisfied
○ Slightly satisfied ○ Extremely satisfied

**55. Form filled out by**

○ Patient with no assistance
○ Patient with assistance
○ Family member/friend
○ Paid caregiver

## ALSA-Q5 Health Assessment Questionnaire:

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The following statements all refer to certain difficulties that you may have had during the last 2 weeks. Please indicate, by checking the appropriate line, how often the following statements have been true for you.

If you cannot do the activity at all please check Always/cannot do at all.

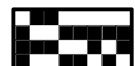
**56. How often during the last 2 weeks have the following been true?**

| | Never | Rarely | Sometimes | Often | Always / Cannot do at all |
|---|---|---|---|---|---|
| a. I have found it difficult to stand up | ○ | ○ | ○ | ○ | ○ |
| b. I have had difficulty using my arms and hands | ○ | ○ | ○ | ○ | ○ |
| c. I have had difficulty eating solid food | ○ | ○ | ○ | ○ | ○ |
| d. I have felt that my speech has not been easy to understand | ○ | ○ | ○ | ○ | ○ |
| e. I have felt hopeless about the future | ○ | ○ | ○ | ○ | ○ |

**57. Is there a history in your family (i.e., blood relatives) of any of the following neurodegenerative diseases?**

| | | | |
|---|---|---|---|
| a. | Alzheimer's Disease | ○ Yes | ○ No |
| b. | Parkinson's disease | ○ Yes | ○ No |
| c. | ALS | ○ Yes | ○ No |
| d. | Other _______________ | ○ Yes | ○ No |





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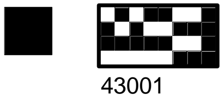

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# PATIENT FORM

ALS PATIENT CARE DATABASE

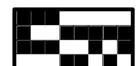
**58. Please respond concerning your experience with the following sources of information:**

| Information Sources | Check if available to you (Check all that apply) | Check sources that have given you help (Check all that apply) | Check MOST VALUABLE source of ALS info. (Check one) |
|---|---|---|---|
| a. Muscular Dystrophy Assoc. | O | O | O |
| b. ALS Association (ALSA) | O | O | O |
| c. Nat. Org. for Rare Diseases | O | O | O |
| d. Veterans Affairs (VA) | O | O | O |
| e. ALS support group | O | O | O |
| f. Religous organization | O | O | O |
| g. Hospice | O | O | O |
| h. Home Health Agency | O | O | O |
| i. ALS Society of Canada | O | O | O |
| j. Internet | O | O | O |
| k. Community Neurologist | O | O | O |
| l. ALS Specialty Clinic | O | O | O |
| m. Other health care provider | O | O | O |
| n. Other ______________ | O | O | O |

**59. Have you EVER been told by a doctor or other health professional that you had … (Check yes or no for each condition listed.)**

| | Yes | No | If yes, are you currently receiving treatment? Yes | No |
|---|---|---|---|---|
| a. Blindness or trouble seeing even when wearing glasses or contact lenses | O | O | O | O |
| b. Deafness or difficulty hearing even when wearing a hearing aid | O | O | O | O |
| c. Depression | O | O | O | O |
| d. Diabetes or sugar diabetes | O | O | O | O |
| e. Coronary heart disease | O | O | O | O |
| f. Hypertension, also called high blood pressure | O | O | O | O |
| g. Stroke | O | O | O | O |
| h. Kidney disease | O | O | O | O |
| i. Liver disease (such as cirrhosis or hepatitis) | O | O | O | O |
| j. Lung disease (not related to ALS) | O | O | O | O |
| k. Anemia or other blood problems | O | O | O | O |
| l. Lymph node cancer (lymphoma) | O | O | O | O |
| m. Bone marrow cancer (myeloma) | O | O | O | O |
| n. Other cancer (not including skin cancer) | O | O | O | O |
| o. Menopause or surgical removal of both ovaries | O | O | O | O |
| p. Neurologic disease (other than ALS) | O | O | O | O |
| q. Bone/joint disease (such as osteoporosis or arthritis) | O | O | O | O |
| r. Sciatica or chronic back problem | O | O | O | O |
| s. Skin disorder | O | O | O | O |
| t. Thyroid disease | O | O | O | O |
| u. Ulcer or stomach disease | O | O | O | O |





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