HEALTH PROFESSIONAL FORM

ALS PATIENT CARE DATABASE

42957

Physicians or their designee should complete this form for each ALS patient at routine visits. Start with the visit at which you first enroll the patient and repeat at routine follow-up visits. If the patient has expired or the diagnosis of ALS has been ruled out, please complete the ALS Patient Care Database: Completion Form.

1. Patient ID

2. Clinic/Site ID

3. Physician ID

4. Exam date (month/day/year)

/ / 200 / 2000

5. Patient weight

O lbs. O kgs. O not done

6. Is this the first time you have filled out this form for this patient?

O Yes O No If Yes, complete questions 7-11. If No, go to question 12.

Diagnosis: Complete only at enrollment visit

7. Onset of ALS symptoms

/

Month Year

8. Date ALS diagnosed

/

Month Year

9. Surgery since ALS symptom onset (check all that apply)

O Lumbar spine surgery O Peripheral nerve surgery

O Cervical spine surgery O None

10. Type of ALS?

O Sporadic O Familial

11. Region of initial site of diagnosis:

O Bulbar O Cervical O Thoracic O Lumbar

Assessment: Complete at every visit

12. Atypical features insufficient to rule out ALS to date (at enrollment visit) or since the last ALS form was completed (at follow-up visits) (check all that apply):

O None O Extrapyramidal features

O Bladder dysfunction O Cognitive change

O Sensory dysfunction O Ataxia

O Autonomic dysfunction O Other

specify: _____

13. Region(s) affected by ALS (check all that apply):

	UMN	LMN	EMG Confirmed
Bulbar	O	O	O
Cervical	O	O	O
Thoracic	O	O	O
Lumbar	O	O	O

ALS Functional Rating Scale (see back of page)

14. ALS Functional Rating Scale

	4	3	2	1	0
1. Speech	O	O	O	O	O
2. Salivation	O	O	O	O	O
3. Swallowing	O	O	O	O	O
4. Handwriting	O	O	O	O	O
5. Cutting food	O	O	O	O	O
6. Dressing and hygiene	O	O	O	O	O
7. Turning in bed	O	O	O	O	O
8. Walking	O	O	O	O	O
9. Climbing stairs	O	O	O	O	O
10. Dyspnea	O	O	O	O	O
11. Orthopnea	O	O	O	O	O
12. Respiratory insufficiency	O	O	O	O	O

Current Management: Complete at every visit

15. El Escorial Diagnostic Criteria (see back of page)

O Suspected O Probable O Definite

O Possible O Lab-Supported Probable

16. Is the patient enrolled in a controlled clinical ALS trial? (includes expanded access programs.)

O Yes O No Specify trial name: _____

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Which of the following interventions have been used to date (at enrollment visit) or since the last ALS form was completed (at follow-up visits)?

17. Medications for ALS (listed alphabetically)	Yes	No
a. Creatine	O	O
b. Gabapentin	O	O
c. High-dose Vitamin E (>1000U/day)	O	O
d. Non-traditional medications	O	O
e. Other high-dose vitamins or antioxidants	O	O
f. Riluzole	O	O
g. Other prescription medications	O	O

specify: _____

18. Therapeutic interventions	Yes	No
a. Ankle-foot orthosis (AFO)	O	O
b. Cane	O	O
c. Walker	O	O
d. Wheelchair for long excursions	O	O
e. Total dependency on wheelchair	O	O
f. Head or neck support	O	O
g. Communication device: low tech	O	O
h. Communication device: computer	O	O
i. Paid attendant (e.g. for ADL needs)	O	O

Respiratory Support: Complete at every visit

19. Vital Capacity (VC or FVC - highest value): O not done

% predicted ☐☐☐ liters ☐.☐☐

20. Respiratory interventions	Yes	No	Declined
a. NPPV (e.g., BiPAP) (non-invasive positive pressure ventilator)	O *	O	O
b. Suction	O	O	O
c. In/exsufflator	O	O	O
d. Other non-invasive respiratory assistance	O	O	O
e. Tracheostomy alone	O	O	O
f. Tracheostomy with Ventilator	O	O	O
g. Other	O	O	O

specify: _____

* If Yes to 20a, please complete question 21

21. Indicate time on NPPV

O Night only O Night and part of day O Full time

22. Does the patient currently have any of the following indications for respiratory support? (Check all that apply)

a. Dyspnea	O Yes	O No
b. Excessive daytime sleepiness	O Yes	O No
c. Nocturnal awakenings If Yes, avg. # per night ☐	O Yes	O No
d. Morning headaches	O Yes*	O No

* If Yes, please complete questions 23-25

23. Have you recommended NPPV? O Yes O No

If No, skip to question 26.

If Yes,

a. Date of recommendation ☐☐ / ☐☐ (Month / Year)

b. FVC or VC value at the time of recommendation

% predicted ☐☐☐ liters ☐.☐☐

24. Was invasive (i.e., tracheostomy) ventilation discussed as an elective procedure? O Yes O No

25. Were advanced plans for withdrawal of ventilation discussed? O Yes O No

Nutritional Support: Complete at every visit

Which of the following interventions have been used to date (at enrollment visit) or since the last ALS form was completed (at follow-up visits)?

26. Feeding modalities	Yes	No	Declined
a. Enteral nutritional support	O	O	O
b. Other	O	O	O

specify: _____

27. Does the patient have any of the following indications for enteral nutritional support? (Check all that apply)

	Yes	No
a. Dysphagia	O	O
b. Significant weight loss	O	O
c. Declining pulmonary function	O	O

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If the patient already has a feeding tube, or has no indications for a feeding tube, please go to question 30

28. Have you recommended a Feeding Tube?

O Yes O No

a. If Yes, date of recommendation ☐☐ / ☐☐ (Month / Year)

b. FVC or VC value at the time of recommendation

% predicted ☐☐☐ liters ☐.☐☐

29. Was a Feeding Tube inserted?

O Yes O No

a. If Yes, date of insertion ☐☐ / ☐☐ (Month / Year)

b. FVC or VC value at the time of insertion

% predicted ☐☐☐ liters ☐.☐☐

Comorbid Conditions: Complete at every visit

30. Ask the patient which of the following ALS-related conditions have been experienced to date (at enrollment visit) or since the last ALS form was completed (at follow-up visits)? (Check all that apply.)

- O None
- O Traumatic injury
- O Aspiration
- O Pain
- O Depression
- O Anxiety
- O Disturbed sleep
- O Fall
- O Choking
- O Pneumonia
- O Pulmonary embolism
- O E.D. visit(s)
- O Hospital admission
- O Contracture(s)
- O Decubiti
- O Pseudobulbar affect
- O Frozen shoulder
- O Other

specify: _____

31. Does the patient have or has the patient ever had:

a. Menopause or surgical removal of both ovaries

- O No
- O Yes and receiving hormone replacement therapy
- O Yes and NOT receiving hormone replacement therapy
- O Not applicable

b. Thyroid disease

O No O Hyperthyroidism O Hypothyroidism

32. To date, which of the following areas covered by the American Academy of Neurology's ALS Practice Parameter have you implemented and/or discussed with this patient?

- O Breaking the news
- O Symptomatic Management
- O Enteral nutritional support and PEG insertion
- O Palliative care/end-of-life issues
- O Respiratory interventions