COMPLETION FORM

ALS PATIENT CARE DATABASE

42906

Physicians or their designee should complete this form when the diagnosis of ALS has been excluded or after the patient's death.

1. Patient ID

2. Clinic/Site ID

3. Physician ID

4. From whom was this data obtained?

O MD / physician O Other health professional
O Caregiver or spouse O Other relative O Other

5. Patient status changed because:

O ALS diagnosis excluded O Patient expired
O Lost to follow-up

6. Month and year of change: ___ / ___ (Month / Year)

Please answer the remaining questions only if the patient has died.

7. Cause of death (check all that apply):

O Respiratory O Unexpected/sudden O Unknown
O Cardiac O Related to ALS
O Suicide O Unrelated to ALS

8. Place of death:

O Hospice O Skilled nursing facility O Other
O Hospital O Home O Unknown

a. Were Hospice services used?

O Yes O No O Unknown

b. If Yes, how long? ___ days

c. How would you rate the quality of communication between the ALS clinic team and Hospice service team?

O High O Low O No communication

9. Considering the 3 day period prior to death, would you say the patient died peacefully?

O Yes O No O Unknown

9a. In the 3 days preceding death, did the patient have (check all that apply):

O Breathing difficulty / respiratory distress
O Nausea O Pain O Insomnia
O Stridor O Choking O Anxiety or fear

10. In the 3 days preceding death, were medications given to control pain or distress?

O Yes O No O Unknown

If Yes, please check the box correspnding with the route of administration for each type of medication administered (check all that apply):

Medication Type	Parenteral	Enteral	Both
a. Opiates	O	O	O
b. Benzodiazepines	O	O	O
c. Non-steroidal anti-inflammatory	O	O	O
d. Antidepressants	O	O	O
e. Other (specify) _____	O	O	O

	Long Term	Preterminal (last 3 days) only	No	Unknown
11. a. Was oxygen given?	O	O	O	O
b. Was BiPaP given?	O	O	O	O
c. Did the patient have a feeding tube?	O	O	O	O
d. Did the patient have a tracheostomy?	O	O	O	O

e. Oxygen Started ___ / ___ (Month / Year)

f. Feeding Tube Started ___ / ___ (Month / Year)

12. Was an autopsy performed?

O Yes O No O Unknown

13. Did you (the physician) ask to have an autopsy peformed?

O Yes O No O Unknown

14. Were advance directives in place?

O Yes O No O Unknown

15. Were advance directives followed?

O Yes O No O Unknown

Comments:

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