HOSPICE TERMINAL PROGNOSIS
Amyotrophic Lateral Sclerosis

WHAT IS THE SIX-MONTH TERMINAL PROGNOSIS?

To be eligible for the hospice benefit, the patient must be considered to be terminally ill. Terminally ill means that the patient's life expectancy is 6 months or less, if the illness runs its normal course.

As a condition of payment under the Medicare hospice benefit, the six-month terminal prognosis must be supported in the medical record. The physician's clinical judgment must be supported by clinical information and other documentation that provides a basis for the six-month prognosis. Diagnosis alone may not support terminal prognosis; therefore, documentation in the medical record must support the terminal status.

DISEASE SPECIFIC GUIDELINES

General Considerations:

1. ALS tends to progress in a linear fashion over time. Thus the overall rate of decline in each patient is fairly constant and predictable, unlike many other non-cancer diseases.
2. However, no single variable deteriorates at a uniform rate in all patients. Therefore, multiple clinical parameters are required to judge the progression of ALS.
3. Although ALS usually presents in a localized anatomical area, the location of initial presentation does not correlate with survival time. By the time patients become end-stage, muscle denervation has become widespread, affecting all areas of the body, and initial predominance patterns do not persist.
4. Progression of disease differs markedly from patient to patient. Some patients decline rapidly and die quickly; others progress more slowly. For this reason, the history of the rate of progression in individual patients is important to obtain to predict prognosis.
5. In end-state ALS, two factors are critical in determining prognosis: ability to breathe, and to a lesser extent ability to swallow. The former can be managed by artificial ventilation, and the latter by gastrostomy or other artificial feeding, unless the patient has recurrent aspiration pneumonia. While not necessarily a contraindication to Hospice Care, the decision to institute either artificial ventilation or artificial feeding will significantly alter six-month prognosis.
6. Examination by a neurologist within three months of assessment for hospice is advised, both to confirm the diagnosis and to assist with prognosis.

Patients will be considered to be in the terminal stage of ALS (life expectancy of six months or less) if they meet the following criteria. (Should fulfill 1, 2, or 3):

NOTE: These guidelines are to be used in conjunction with the "Non-disease specific baseline guidelines" described in Part II of the basic policy.

1. Patient should demonstrate critically impaired breathing capacity.
    a. Critically impaired breathing capacity as demonstrated by all the following characteristics occurring within the 12 months preceding initial hospice certification:
        i. Vital capacity (VC) less than 30% of normal (if available);
        ii. Dyspnea at rest;
        iii. Patient declines mechanical ventilation; external ventilation used for comfort measures only.
2. Patient should demonstrate both rapid progression of ALS and critical nutritional impairment.
    a. Rapid progression of ALS as demonstrated by all the following characteristics occurring within the 12 months preceding initial hospice certification:

i. Progression from independent ambulation to wheelchair to bed bound status;
ii. Progression from normal to barely intelligible or unintelligible speech;
iii. Progression from normal to pureed diet;
iv. Progression from independence in most or all activities of daily living (ADLs) to needing major assistance by caretaker in all ADLs.

b. Critical nutritional impairment as demonstrated by all the following characteristics occurring within the 12 months preceding initial hospice certification:

i. Oral intake of nutrients and fluids insufficient to sustain life;
ii. Continuing weight loss;
iii. Dehydration or hypovolemia;
iv. Absence of artificial feeding methods, sufficient to sustain life, but not for relieving hunger.

3. Patient should demonstrate both rapid progression of ALS and life-threatening complications.

a. Rapid progression of ALS, see 2.a above.
b. Life-threatening complications as demonstrated by one of the following characteristics occurring within the 12 months preceding initial hospice certification:

i. Recurrent aspiration pneumonia (with or without tube feedings);
ii. Upper urinary tract infection, e.g., pyelonephritis;
iii. Sepsis;
iv. Recurrent fever after antibiotic therapy;
v. Stage 3 or 4 decubitus ulcer(s).

PART II. NON-DISEASE SPECIFIC BASELINE GUIDELINES (BOTH OF THESE SHOULD BE MET)

1. Physiologic impairment of functional status as demonstrated by: Karnofsky Performance Status (KPS) or Palliative Performance Score (PPS) <70%.
2. Dependence on assistance for two or more activities of daily living (ADLs)

a. Feeding
b. Ambulation
c. Continence
d. Transfer
e. Bathing
f. Dressing

PART III. CO-MORBIDITIES

Although not the primary hospice diagnosis, the presence of disease such as the following, the severity of which is likely to contribute to a life expectancy of six months or less, should be considered in determining hospice eligibility.

a. Chronic obstructive pulmonary disease
b. Congestive heart failure
c. Ischemic heart disease
d. Diabetes mellitus
e. Neurologic disease (CVA, ALS, MS, Parkinson's)
f. Renal failure
g. Liver Disease
h. Neoplasia
i. Acquired immune deficiency syndrome
j. Dementia

WHERE DO I FIND MORE INFORMATION?

- Medicare Benefit Policy Manual (CMS Pub. 100-02), Ch. 9: https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/bp102c09.pdf
- Local Coverage Determination (LCD) L34538, "Hospice Determining Terminal Status": https://www.cgsmedicare.com/hhh/coverage/index.html