# Measure #10: ALS End of Life Planning Assistance

*Amyotrophic Lateral Sclerosis*

## Measure Description

Percentage of patients diagnosed with ALS who were offered at least once annually assistance in planning for end of life issues (eg advance directives, invasive ventilation, hospice).

## Measure Components

<table>
<thead>
<tr>
<th>Numerator Statement</th>
<th>Patients who were offered at least once annually assistance in planning for end of life issues (eg advance directives, invasive ventilation, or hospice).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denominator Statement</td>
<td>All patients with a diagnosis of amyotrophic lateral sclerosis.</td>
</tr>
<tr>
<td>Denominator Exclusions</td>
<td>Documentation of a medical reason for not offering at least once annually assistance in planning for end of life issues (eg patient in hospice and already in terminal phase)</td>
</tr>
</tbody>
</table>

## Supporting Guideline & Other References

The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines and represent the evidence base for the measure:

- Advance directives for palliative end-of-life care should be discussed early with the patient and carers, respecting the patient's social and cultural background.¹
- Offer assistance in formulating an advance care directive. (GPP)²
- Review the patients’ wishes regarding their care and advance directives regularly. (Level II)³
- Re-discuss the patient’s preferences for life-sustaining treatments every 6 months. (GPP)²
- Initiate discussions on end-of-life issues whenever the patient asks or “opens the door” for end-of-life information and/or interventions. (GPP)²
- Treat pain in ALS following accepted guidelines. (GPP)²
- Initiate early referral to hospice or home care teams well in advance of the terminal phase of ALS to facilitate the work of the hospice team. (GPP)²
- Discuss options for respiratory support and end-of-life issues if the patient has dyspnea, other symptoms of hypoventilation or VC <50%. (GPP)²
- Treat terminal dyspnea and/or pain with opioids alone or in combination with benzodiazepines if anxiety is present. (GPP)²


Referral to palliative services occurs varies considerably across different countries. End of life discussions will improve patient decision making with respect to disease management. Offering assistance in formulating an advanced care directive can initiate this discussion and re-discussion of the patient’s preferences for life-sustaining treatments every 6 months. Pain in ALS should be treated following accepted guidelines. Physical therapy will aid in treating spasticity and pain. Discussion of respiratory support if the patient has dyspnea, other symptoms of hypoventilation or VC <50% will allow patient to choose intervention or hospice. Early referral to hospice or home care team will in advance of the terminal phase of ALS will facilitate the work of the hospice team and improve patient transition to hospice. A medical social worker can help with financial issues. Medications for terminal dyspnea, pain and/or anxiety will improve quality of life.

References

Opportunity for Palliative care should be adopted from the time of diagnosis. Many patients are not
Improvement

adequately informed about advance directives and end of life decision making and many hospice workers are not familiar with ALS. Management of the terminal phase of ALS is unsatisfactory in 33% - 61% of cases in Europe and only 8% of palliative care units are involved from the time of diagnosis. The current system of palliative care in the USA is highly decentralized. Between 60-88% of patients die in a medical facility in some countries and not at home, while over 58% of seriously ill ALS patients do not have hospice care. Approaches to end of life care vary widely and are not standardized either in timing or content.

References


<table>
<thead>
<tr>
<th>IOM Domains of Health Care Quality Addressed</th>
<th>Effective Patient centered Timely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exclusion Justification</td>
<td>A medical reason exclusion has been included for patients who are already in hospice and in the terminal phase.</td>
</tr>
</tbody>
</table>

Harmonization with Existing Measures

There exist two other measures that refer to advanced care planning. The American Geriatrics Society (2008) has a measure “Percentage of patients aged 65 years and older who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan.” However this measure is limited to those over the age of 65. The work group felt it was important to not exclude patients under 65 years old who have ALS from an end of life planning measure. In addition, the Institute for Clinical Systems Improvement (ICSI) (2009) has a measure that states the “Percentage of adult patients with the specified progressive, debilitating disease who have a palliative care plan* in chart.” *A completed palliative care plan addresses all seven domains of care: physical aspects, cultural aspects, psychological aspects, social aspects, spiritual/religious/existential aspects, ethical/legal aspects.
aspects, and care of the imminently dying patient. However, this measure does not reference specific end of life needs that are relevant for patients with ALS. This measure was also not developed by a medical specialty society and the methods used to develop the measure are unclear.

### Measure Designation

| Measure purpose          | • Quality improvement  
|                          | • Accountability      |
| Type of measure          | • Process             |
| Level of Measurement     | • Individual practitioner |
| Care setting             | • Ambulatory Care     |
| Data source              | • Electronic health record (EHR) data  
|                          | • Administrative Data/Claims (inpatient or outpatient claims)  
|                          | • Administrative Data/Claims Expanded (multiple-source)  
|                          | • Paper medical record |

### Technical Specifications: Administrative/Claims Data

Administrative claims data collection requires users to identify the eligible population (denominator) and numerator using codes recorded on claims or billing forms (electronic or paper). Users report a rate based on all patients in a given practice for whom data are available and who meet the eligible population/denominator criteria.

The specifications listed below are those needed for performance calculation. Additional CPT II codes may be required depending on how measures are implemented. (Reporting vs. Performance)

**Denominator (Eligible Population)**

<table>
<thead>
<tr>
<th>ICD-9 –CM Diagnosis Codes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>335.20 amyotrophic lateral sclerosis AND</td>
</tr>
<tr>
<td>CPT E/M Service Code:</td>
</tr>
<tr>
<td>99201, 99202, 99203, 99204, 99205 (office-new patient),</td>
</tr>
<tr>
<td>99211,99212, 99213, 99214, 99215 (office-established patient),</td>
</tr>
<tr>
<td>99241, 99242, 99243, 99244, 99245 (outpatient consult),</td>
</tr>
<tr>
<td>99304, 99305, 99306, 99307, 99308, 99309, 99310 (nursing facility),</td>
</tr>
<tr>
<td>99324, 99325, 99326, 99327, 99328, 99334, 99335, 99336, 99337 (domiciliary),</td>
</tr>
<tr>
<td>99341, 99342, 99343, 99344, 99345, 99347, 99348, 99349, 99350 (home visit)</td>
</tr>
</tbody>
</table>

**Numerator**

Patients who were offered at least once annually assistance in planning for end of life issues (e.g., advance directive, invasive ventilation, or hospice).

**Reporting Instructions:**

- For all patients meeting denominator criteria, report the CPT Category II, 4553F Patient offered assistance in planning for end of life issues

**Denominator Exclusions**

All patients with a diagnosis of amyotrophic lateral sclerosis.

- Documentation of a medical reason for not offering at least once annually assistance in planning for end of life issues at least once annually (e.g., patient in hospice and already in terminal phase)

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Reporting Instructions:
  - For patient with appropriate exclusion criteria, report: 4553F-1P