

Data from 2014 Stakeholder Survey Regarding Questions

	Yes, Definitely	Yes, Probably	Could be dropped to make room for other questions	Should not be included	Don't Know	Blank
When is PEG indicated in ALS?	86%	5%	10%	0%	0%	0%
What are the optimal pulmonary tests to detect respiratory insufficiency?	86%	10%	0%	5%	0%	0%
What are the most effective treatments for sialorrhea?	81%	19%	0%	0%	0%	0%
Does multidisciplinary management improve outcomes?	76%	24%	0%	0%	0%	0%
Does NIV improve respiratory function or increase survival?	76%	24%	0%	0%	0%	0%
How do invasive and non-invasive ventilation affect quality of life?	67%	33%	0%	0%	0%	0%
What is the efficacy of nutritional support via PEG in prolonging survival?	67%	33%	0%	0%	0%	0%
What is the efficacy of targeted respiratory interventions for clearing secretions?	67%	29%	0%	5%	0%	0%
What pharmacologic measures reduce pseudobulbar affect?	67%	29%	0%	0%	0%	5%
Who should have ALS genetic screening?	67%	29%	0%	5%	0%	0%
Which genetic tests should be considered in sporadic and familial ALS?	67%	24%	10%	0%	0%	0%
What is the effect of enteral nutrition delivered via PEG on quality of life?	62%	29%	5%	5%	0%	0%
What is the effect of riluzole on slowing the disease process or prolonging survival in ALS?	62%	14%	24%	0%	0%	0%
How is cognitive or behavioral impairment in ALS diagnosed?	57%	24%	10%	10%	0%	0%
What treatments reduce pain and dyspnea in the terminal phase of ALS?	57%	38%	0%	5%	0%	0%
Do hospice care, spiritual interventions, or advance directive improve quality of life in the terminal phase of ALS?	57%	24%	14%	5%	0%	0%
What interventions reduce spasticity?	52%	38%	10%	0%	0%	0%

What is the prevalence and natural history of cognitive and behavioral impairment in ALS?	52%	19%	14%	10%	5%	0%
What is the optimal method of withdrawing both non-invasive and invasive ventilation in ALS?	52%	33%	5%	10%	0%	0%
What is the maximum amount of time that a patient should have to wait for BIPAP initiation after BIPAP has been clinically recommended?	52%	19%	14%	10%	5%	0%
What is the effect of enteral nutrition administered via PEG on weight stability?	48%	19%	29%	0%	0%	5%
What interventions reduce cramps?	48%	38%	14%	0%	0%	0%
What treatments are effective for cognitive or behavioral impairment in ALS?	48%	38%	10%	5%	0%	0%
What treatments for dysarthria optimize communication in ALS?	48%	33%	14%	5%	0%	0%
How are bronchial secretions best treated in ALS?	48%	48%	5%	0%	0%	0%
What is the maximum amount of time that a patient should have to wait for REG/RIG insertion, after it has been clinically recommended?	48%	14%	19%	10%	10%	0%
When should palliative care be invited to participate in the care of ALS patients?	48%	33%	14%	5%	0%	0%
What factors influence acceptance of invasive and non-invasive ventilation?	43%	24%	29%	5%	0%	0%
What are the recommended investigations when investigating ALS?	43%	29%	29%	0%	0%	0%
What is the effect of cognitive or behavioral impairment on management of patients with ALS?	38%	33%	19%	10%	0%	0%
Should ALS patients be regularly queried about falls?	38%	24%	33%	5%	0%	0%
What is the maximum amount of time a patient with possible ALS should have to wait to see an ALS specialist?	38%	19%	24%	19%	0%	0%
How should a physician tell patients that they have ALS?	33%	29%	24%	14%	0%	0%
Which diseases can masquerade as ALS?	33%	24%	33%	10%	0%	0%
What is the risk of DVT in patients with ALS?	33%	33%	29%	5%	0%	0%
What is the maximum amount of time a patient with possible ALS should have to wait to have EMG studies?	33%	19%	24%	19%	5%	0%
What grief counselling should be offered to caregivers of deceased patients with ALS?	33%	29%	24%	10%	5%	0%
What pharmacologic interventions reduce depression?	29%	48%	24%	0%	0%	0%
What pharmacologic interventions reduce anxiety?	29%	38%	33%	0%	0%	0%
What pharmacologic interventions reduce insomnia?	29%	19%	48%	0%	0%	5%
What is the burden of care for ALS caregivers?	29%	38%	14%	19%	0%	0%
Should DVT prophylaxis be considered in patients with ALS?	29%	33%	33%	5%	0%	0%
What pharmacologic interventions reduce fatigue?	24%	52%	19%	5%	0%	0%
What is the efficacy of vitamin and nutritional supplements on	14%	24%	38%	19%	0%	5%

prolonging survival or quality of life?				%		
<b>Open-Ended Response: Other questions</b>						
Timing for end of life discussions						
Prevalence and type of pain in ALS patients Is there a treatment for fasciculations?						
Does a case manager improve quality of life of patients ofr families of those with ALS						
Community Resources , ALS Clin9cs in Canada ASL Society Life directives, legal, wills etc						
What level of physical exercise is recommended in patients with ALS?						
Having guidelines as a series of questions and answers has its limitations.I think we should discuss the format of the guidelines and who we think will use them. Both the AAN and EFNS are in the question/topic mode. I think we should consider dissemination and utility as well as symptom/intervention.						