

Appendix 1:

New ALS Patient Questionnaire

1. Patient Demographics:

- a. Age: _____
- b. Gender: ☐ M ☐ F
- c. Race: ☐ Hispanic ☐ Caucasian ☐ African American ☐
Other: _____

2. Health Care Utilization:

- a. Where did you receive medical care for ALS prior to coming to the VA?

- b. What type of doctor did you see? ☐ Primary care ☐ Family
☐ Neurologist ☐ Other _____
- c. Have you been seen by a Neurologist since you had ALS? ☐ Yes ☐ No

3. Health Information/Care:

During your previous medical care:

- 1. Was education about ALS Management provided to you? ☐ Yes ☐ No
If yes, please indicate how satisfied you were with the ALS management education that you received:
☐ Very satisfied ☐ Satisfied ☐ Neutral ☐ Dissatisfied ☐ Very dissatisfied
- 2. Were you evaluated by a Speech Therapist? ☐ Yes ☐ No
If yes, please indicate how satisfied you were with the ALS management education that you received:
☐ Very satisfied ☐ Satisfied ☐ Neutral ☐ Dissatisfied ☐ Very dissatisfied
- 3. Was Tracheostomy placement discussed with you? ☐ Yes ☐ No
If yes, please indicate how satisfied you were with the ALS management education that you received:
☐ Very satisfied ☐ Satisfied ☐ Neutral ☐ Dissatisfied ☐ Very dissatisfied
- 4. Was a PEG Tube Placement discussed with you? ☐ Yes ☐ No
If yes, please indicate how satisfied you were with the ALS management education that you received:
☐ Very satisfied ☐ Satisfied ☐ Neutral ☐ Dissatisfied ☐ Very dissatisfied

5. Were you evaluated by an Occupational Therapist for Equipment Needs? ☐ Yes ☐ No

If yes, please indicate how satisfied you were with the ALS management education that you received:

☐ Very satisfied ☐ Satisfied ☐ Neutral ☐ Dissatisfied ☐ Very dissatisfied

6. Was a Home Evaluation done? ☐ Yes ☐ No

If yes, please indicate how satisfied you were with the ALS management education that you received:

☐ Very satisfied ☐ Satisfied ☐ Neutral ☐ Dissatisfied ☐ Very dissatisfied

7. Was the prognosis of ALS (disease course & outcomes) discussed with you? ☐ Yes ☐ No

If yes, please indicate how satisfied you were with the ALS management education that you received:

☐ Very satisfied ☐ Satisfied ☐ Neutral ☐ Dissatisfied ☐ Very dissatisfied

8. Was the End of Life care discussed with you? ☐ Yes ☐ No

If yes, please indicate how satisfied you were with the ALS management education that you received:

☐ Very satisfied ☐ Satisfied ☐ Neutral ☐ Dissatisfied ☐ Very dissatisfied