

Supplemental Material S1. Pre-evaluation questionnaire.

Name: _____

Date of Birth: _____

Hi,

I am a speech pathologist who has specialized in augmentative communication for people with ALS for over 20 years.

I'm excited to help you find some communication solutions. Please answer the following questions so I can plan for the tools and strategies we will explore together.

Many of the responses are check-boxes to save you time and energy (click on a box to mark it) but feel free to add any additional information you think would be helpful. If you are uncertain of a response, highlight or mark it and we can discuss it during our first meeting.

1. Please list any languages other than English in which you communicate?

2. Do you or any of your communication partners have a hearing loss?
Multiple boxes can be selected.
 Yes, I have a hearing loss.
 Yes, one or more of my communication partner's has a hearing loss.
 No

3. Do you wear glasses or contacts when using a computer?
Multiple boxes can be selected.
 Yes, single prescription.
 Yes, bifocals.
 Yes, progressives.
 Yes, contacts
 No

4. Do you have any of the following eye conditions?
Multiple boxes can be selected.
 Astigmatism
 Double vision
 Dry eyes
 Difficulty opening or closing eyes completely
 Droopy eye lids
 Irregular eye movements or lack of ability to move eyes
 Other: _____

5. What was your date of diagnosis with ALS?
6. What was the approximate month and year of your first symptom of ALS?
7. What was your first symptom?
8. What was the approximate month and year that you first experienced, or others noticed, a change in your speech?
9. What was the approximate month and year you began to experience hand or arm weakness?
10. Are you using any equipment to help you to move around and where do you use it? Multiple boxes can be selected.

- | | | |
|-------------------|--------------------------------------|---------------------------------------|
| Cane | <input type="checkbox"/> Inside home | <input type="checkbox"/> Outside home |
| Walker | <input type="checkbox"/> Inside home | <input type="checkbox"/> Outside home |
| Manual wheelchair | <input type="checkbox"/> Inside home | <input type="checkbox"/> Outside home |
| Power wheelchair | <input type="checkbox"/> Inside home | <input type="checkbox"/> Outside home |

11. How often do you go out into the community? Select only ONE box.
 - Daily
 - A few times per week
 - A few times per month
 - A few times per year
 - Never
12. If you currently use a wheelchair/s what is/are the make and model? (e.g. Permobil M300, Quantum Edge, Invacare TDX, Pride Jazzy, etc.)
13. Describe any difficulty you experience with writing? Select only ONE box.
 - I can write clearly and without fatigue.
 - I experience some fatigue, slowness, or loss of legibility with writing.
 - Writing is very fatiguing or my writing can be hard to read.
 - I am only able to write a word or two.
 - I am unable to write.
14. Describe any problems you have with keyboarding/typing? Multiple boxes can be selected.
 - I can keyboard normally and without fatigue.
 - I experience some fatigue, slowness, or inaccuracy with keyboarding.

- Keyboarding is very fatiguing, slow, or I make frequent errors.
 - I can only use one hand for keyboarding.
 - I only use a single finger for keyboarding.
 - I am unable to use a keyboard with my hands.
 - _____
15. Describe any problems you have moving a mouse? Multiple boxes can be selected.
- I have no problem moving a mouse.
 - I experience some fatigue, slowness, or inaccuracy with mousing.
 - Mousing is very fatiguing or slow.
 - I have to use my non-dominant hand for mousing.
 - I use a mouse alternative with my hand (touchpad, ergonomic, or adapted, etc.).
 - I am unable to use my hands to operate a mouse or mouse alternative.
16. Describe any problems you have clicking on a mouse? Multiple boxes can be selected.
- I have no problem with right, left or double clicking.
 - I experience some fatigue, slowness or inaccuracy with mouse clicks.
 - I can move a mouse but can't do any clicking.
 - am unable to use a mouse with my hands.
 - I use an alternative method for mouse clicks (dwell, switch, etc.): _____

Questions 13 – 17 ask you about weakness in various parts of your body. For these questions, use the following key for choosing the answer that best fits your abilities.

***Key**

- Mild:** Movements in this part of my body may be slower or may lack previous accuracy. Activities with this part of my body are possible with independence but may be fatiguing.
- Moderate:** Activities with this part of my body require at least occasional assistance or modifications due to weakness, fatigue or slowness.
- Severe:** The movement in this part of my body may be very slow, minimal, highly fatiguing or not possible. Activities utilizing this part of my body require assistance.

17. Are you experiencing any finger weakness? (use key above)
- No weakness
 - Mild
 - Moderate
 - Severe

18. Are you experiencing any wrist weakness?
- No weakness
 - Mild
 - Moderate
 - Severe
19. Are you experiencing any biceps/triceps weakness (i.e. bending or straitening elbow)?
- No weakness
 - Mild
 - Moderate
 - Severe
20. Are you experiencing any shoulder weakness?
- No weakness
 - Mild
 - Moderate
 - Severe
21. Are you experiencing any neck weakness?
- No weakness
 - Mild
 - Moderate
 - Severe
22. If you have neck weakness do use any of the following supports?
Multiple boxes can be selected.
- Neck collar
 - Wheelchair headrest
 - Other: _____
23. Are you experiencing any neck or shoulder pain?
- Yes
 - No
- If yes, are there certain positions or activities that aggravate the pain?
-

24. How often do people ask you to repeat yourself? Select only ONE box.
- On occasion (approximately once a day)
 - Regularly (many times a day)
 - Most of the time
 - I rarely or no longer use speech for communication
25. If speech is not adequate to communicate at all times, which other methods you use to communicate. Multiple boxes can be selected.
- Writing
 - Communication board (non-electronic)
 - Communication board with only eye movement
 - Responding to yes/no questions. How do you indicate
yes _____ no _____
 - Signs or gestures
 - Other:

26. Do you currently have a way to communicate with people not in your immediate environment? Multiple boxes can be selected.
- I can use my phone for text messaging.
 - I can use my phone for emailing.
 - I can use my phone to dial and speak.
 - I can use a speaker phone if someone else dials.
 - I can use my tablet for emailing.
 - I can use a computer for emailing
 - I don't have a way to communicate with those not in my immediate environment.
27. Do you have an emergency alerting system or caregiver call chime in your home/facility? Multiple boxes can be selected.
- I have a reliable caregiver call chime I can use within my home/facility.
 - I do not have a caregiver call chime that reliably works for me.
 - I am able to use an emergency call chime to reach people outside of my home.
 - I am not able to reach people outside of my home in an emergency.
28. Do you spend more than a just few minutes alone in a room at times?
- Yes
 - No

29. Do you spend time alone in your home each day?

- Yes
- No

30. Have you worked with a speech therapist (aka: SLP, speech language pathologist) since your diagnosis with ALS? Multiple boxes can be selected.

- Yes-from a home health agency In the past Currently
- Yes-at an outpatient clinic In the past Currently
- Yes-at the facility or hospital where I reside In the past Currently
- No- I have not worked with a speech therapist since I was given a diagnosis of ALS

31. If you answered YES to question 30
Please provide the name and contact information for the speech therapist if you have it:

Speech therapist name: _____
Speech therapist Email: _____
Speech therapist phone: _____

- Did the speech therapist work with you on ways to improve communication?

- Yes
- No

- If the speech therapist did work with you on improving communication, briefly describe some of the strategies, recommendation or tools she/he offered.

- Did the speech therapist do any of the following: Multiple boxes can be selected.

- Provide information & hands-on training on message banking
- Provide information on message banking
- Provide information & hands-on training on voice banking
- Provide information on voice banking

32. Have you done of the following? Multiple boxes can be selected.

- I have banked messages (recorded messages in my own voice).
- I have voice banked and created my own synthesized voice. Program used: _____
- I started voice banking but didn't complete it. Program used: _____
- I have extensive recordings of my own voice.

33. Select your seating for various activities. Multiple boxes can be selected. If you are currently unable to do an activity but hope to in the future with technology, mark “Currently unable” and also where you would likely be seated to do this activity.

Activity	Power wheelchair	Manual wheelchair	Bed	Easy chair	Sofa	Standard chair	Currently unable
Computer work & Email	<input type="checkbox"/>						
Phone	<input type="checkbox"/>						
Watching TV	<input type="checkbox"/>						
Reading	<input type="checkbox"/>						
Medical appointments	<input type="checkbox"/>						
Concerts, events, services, sports, etc.	<input type="checkbox"/>						
Speaking to groups	<input type="checkbox"/>						
Socializing at home	<input type="checkbox"/>						
Socializing away from home	<input type="checkbox"/>						
Hobby - _____	<input type="checkbox"/>						
Meals	<input type="checkbox"/>						
Riding in auto, van, bus	<input type="checkbox"/>						
Sleeping	<input type="checkbox"/>						
	<input type="checkbox"/>						

34. What technology do you already own? Multiple boxes can be selected.

- Model or Operating System
- Tablet: Windows 10 iPad Android Other _____

- Desktop: Windows 10 Mac Other _____
 Laptop: Windows 10 Mac Other _____
 Smartphone: iPhone Android Other _____

35. Describe the internet connection in your home/facility?

- I have reliable internet.
 The internet can be unreliable.
 I don't have any internet in my home/facility.

Questions 36 and 37 ask about you and your primary communication partners' comfort with technology. To answer these questions, please use the following key:

****Key**

- High:** I use a lot of technology, am very comfortable with setting it up and doing my own problem solving etc.
- Average:** I use much of the same technology that most people do (smart phone, computer). I am comfortable doing most basic things and can do some problem solving, but I occasionally need help from other people.
- Low** While I do use some technology, I use it at a very basic level – just a few functions. I often need help problem solving or setting it up because of my limited knowledge.
- Not comfortable** I either prefer not to use a lot of technology; or when I do I rely heavily on the knowledge of other people to help me.

36. What is your level of comfort with technology? ** (use key above)

- High
 Average
 Low
 Not comfortable

37. Please list your primary communication partners (please include paid caregivers too):

Name	Relationship	How often are they with you?	Partner's comfort level with technology?	Will they join us for the evaluation or trainings?
		<input type="checkbox"/> Daily <input type="checkbox"/> A few times per week	<input type="checkbox"/> High <input type="checkbox"/> Average <input type="checkbox"/> Low	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Some of it

		<input type="checkbox"/> A few times per month <input type="checkbox"/> A few times per year	<input type="checkbox"/> Not Comfortable	<input type="checkbox"/> Maybe
		<input type="checkbox"/> Daily <input type="checkbox"/> A few times per week <input type="checkbox"/> A few times per month <input type="checkbox"/> A few times per year	<input type="checkbox"/> High <input type="checkbox"/> Average <input type="checkbox"/> Low <input type="checkbox"/> Not Comfortable	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Some of it <input type="checkbox"/> Maybe
		<input type="checkbox"/> Daily <input type="checkbox"/> A few times per week <input type="checkbox"/> A few times per month <input type="checkbox"/> A few times per year	<input type="checkbox"/> High <input type="checkbox"/> Average <input type="checkbox"/> Low <input type="checkbox"/> Not Comfortable	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Some of it <input type="checkbox"/> Maybe
		<input type="checkbox"/> Daily <input type="checkbox"/> A few times per week <input type="checkbox"/> A few times per month <input type="checkbox"/> A few times per year	<input type="checkbox"/> High <input type="checkbox"/> Average <input type="checkbox"/> Low <input type="checkbox"/> Not Comfortable	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Some of it <input type="checkbox"/> Maybe

38. Will you have an opportunity to see a doctor face-to-face in the next few months?

- Yes
 No

Please provide the name and contact information for the doctor (important for obtaining equipment)

Doctor's name: _____
 Doctor's Email: _____
 Doctor's phone: _____

39. What insurance/s do you have? _____ (please send copy of front and back of card with this form)

40. What assistance did you, the person with ALS, receive in filling out these questions?
Select only ONE box.

- None.
- I provided all of the content and someone else just marked the boxes or wrote down what I communicated.
- I provided most of the content but someone else helped me decide how to answer some questions and wrote down my answers.
- I provided some of the content but someone else took the lead in answering the items.
- Someone else provided most of the content and filled out this form; the person with the communication difficulty participated minimally or not at all.

If you received assistance filling out these questions, who assisted you?

_____ Date of Completion: _____

Thank you for the time and thought you put into responding to these questions and I look forward to developing solutions with you. Call me with any questions at (xxx) xxx-xxxx.

Thank you,
Amy Roman, M.S., CCC-SLP
Augmentative Alternative Communication Specialist