**Supplementary Material**

**Interview guide for PwALS**

General Information

|  |  |
| --- | --- |
| **Sex M/F** |  |
| **Age** |  |
| **Time since diagnosis (years)** |  |
| **Diagnosis (Bulbar or limb Onset)?** |  |
| **Urban or rural?** |  |

**General Questions**

1. Thinking back from now to your diagnosis, what transitions have made the most impact on you? Prompts
   1. Were the changes gradual or sudden?
2. What aspects of your care and treatment have significantly improved quality of life?

Prompts

* 1. Health resources/access
  2. Health care providers (specific)
  3. The home environment

Community based supports

1. What, if anything could be offered or changed to improve quality of life in patients with ALS?

Prompts

1. ALS Clinics
2. ALS society
3. Homecare
4. Community
5. Have you been given information on following, and when did you receive this information?
   1. Breathing machines or mechanical ventilation
   2. Feeding tube
   3. Assistive technology for communication
   4. Advance care planning

Prompts

1. Do you feel you received this information at the right time?
2. If not, when would you prefer to receive it?
3. What future transitions due to ALS are on your mind/do you worry about/scare you?

Prompts:

1. What are your thoughts on mechanical ventilation (BiPAP)?
2. What are your thoughts regarding assistive technology for communication?
3. What are your thoughts around using a feeding tube for nutrition if it becomes difficult to eat?
4. Follow Up to Question 5 (Only ask if Applicable)
5. **If they utilize Assistive Technology for communication**: Has assistive technology improve QOL?
   * 1. If yes, what specific ways has AT improved QOL?
     2. If no, why not?
6. **If they utilize Mechanical Ventilation**: Has mechanical ventilation improved QOL?
   * 1. If yes, what specific ways has MV improved QOL?
     2. If no, why not?
7. **If they have PEG**: Has having the feeding tube improved QOL?
   * 1. If yes, what specific ways?
     2. If no, why not?
8. Is there anything else you would like to tell us?

**Interview Guide for Caregiver**

**General Information**

|  |  |
| --- | --- |
| Sex M/F |  |
| Age |  |
| What is your relationship to the person with ALS? |  |
| What is your employment status?  (Full time, part-time, retired, stay-at-home)  Have you reduced your work hours or altered you career as a result of caregiving? |  |
| How many hours a day/week (on average) do you spend providing direct care to the person with ALS? |  |
| Do you have paid support at home? |  |
| Do you have informal support at home? For example, other family members, friends that help with caregiving? |  |

**Open Ended Questions for Caregiver**

1. Describe the most important transitions that your loved one has had in their ALS journey (from symptom onset until now) and how those transitions have affected you as the caregiver.
2. What have been some of the most difficult aspects of being a caregiver?
3. Is there anything that could be offered or changed to improve the quality of life for you as the caregiver to a person with ALS?
4. Have you been given information on the following, and when did you receive this information?
   1. Mechanical Ventilation/Breathing Machines
   2. Feeding tube
   3. Assistive technology for communication
   4. Advance care planning

Prompts

1. Do you feel you received this information at the right time?
2. If not, when would you prefer to receive it?
3. What transitions do you expect moving forward?

Prompts:

1. What are your thoughts on mechanical ventilation (breathing machines)
2. What are your thoughts regarding assistive technology for communication?
3. What are your thoughts around (person with ALS) using a feeding tube for nutrition if it becomes difficult to eat?
4. Have you found that transition to breathing machines, feeding tubes PEG or communication aids (any applicable one) has improved your QOL as a caregiver?

Prompts

* 1. Have you had to learn new skills to support …?
  2. Have they increased or decreased the time you spend supporting….?

1. We understand that the transitions you experience may be very different and come at different times for you and the person you provide care for. What have been the most significant transitions for you as the caregiver?

Prompts

1. Coping with the disease progression
2. Changing relationship with person with ALS
3. Is there anything else you would like to tell us?