|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Appendix 1. Amyotrophic Lateral Sclerosis Supportive Care Needs Assessment Instrument  (ALSSCN) | | | | |
| Please indicate how much assistance you needed during the last month in performing the following physical activities. | 1  No assistance | 2  Little assistance | 3  Moderate assistance | 4  Considerable assistance |
| 1. Speaking | 1 | 2 | 3 | 4 |
| 1. Drooling | 1 | 2 | 3 | 4 |
| 1. Swallowing food | 1 | 2 | 3 | 4 |
| 1. Using utensils (spoon, fork) or gastrostomy tube | 1 | 2 | 3 | 4 |
| 1. Using the toilet | 1 | 2 | 3 | 4 |
| 1. Bathing | 1 | 2 | 3 | 4 |
| 1. Dressing | 1 | 2 | 3 | 4 |
| 1. Walking | 1 | 2 | 3 | 4 |
| 1. Breathing | 1 | 2 | 3 | 4 |
| 1. Pain | 1 | 2 | 3 | 4 |
| 1. Sleeping problems | 1 | 2 | 3 | 4 |
| Please indicate how much assistance you needed during the last month in overcoming the following problems. | 1  No assistance | 2  Little assistance | 3  Moderate assistance | 4  Considerable assistance |
| 1. Fear about worsening of the disease | 1 | 2 | 3 | 4 |
| 1. Feeling sorry for having to receive assistance from family members in everyday life | 1 | 2 | 3 | 4 |
| 1. Difficulty in accepting the disease | 1 | 2 | 3 | 4 |
| 1. Change in marital relationship (sexual relationship) | 1 | 2 | 3 | 4 |
| 1. Feeling depressed | 1 | 2 | 3 | 4 |
| 1. Feeling lonely | 1 | 2 | 3 | 4 |
| 1. Difficulty in emotional control | 1 | 2 | 3 | 4 |
| Please rate how much assistance and/or special services you needed during the last month for the following topics. | 1  No assistance | 2  Little assistance | 3  Moderate assistance | 4  Considerable assistance |
| 1. Assistance in religious activities | 1 | 2 | 3 | 4 |
| 1. Maintaining human dignity | 1 | 2 | 3 | 4 |
| 1. Getting respect for privacy (personal life) | 1 | 2 | 3 | 4 |
| 1. Care and support from my family | 1 | 2 | 3 | 4 |
| 1. Participating in family and social gathering | 1 | 2 | 3 | 4 |
| 1. Sharing experiences with other ALS patients | 1 | 2 | 3 | 4 |
| 1. Information about disease progression | 1 | 2 | 3 | 4 |
| 1. Information about new drugs or clinical trials | 1 | 2 | 3 | 4 |
| 1. Information about emergency response measures | 1 | 2 | 3 | 4 |
| 1. Information about eligible welfare services | 1 | 2 | 3 | 4 |
| 1. Information about specialists and medical institutions | 1 | 2 | 3 | 4 |
| 1. Assistance with assistive devices (manual/automatic wheelchair, adjustable bed, walker, etc.) | 1 | 2 | 3 | 4 |
| 1. Welfare service with home visits by helpers (professional caregivers) | 1 | 2 | 3 | 4 |
| 1. Financial aids for medical expenses and/or caregiver expenses | 1 | 2 | 3 | 4 |
| 1. Rehabilitation therapy, such as physical therapy and breathing training | 1 | 2 | 3 | 4 |
| 1. Rehabilitation or care facilities for long-term hospitalization | 1 | 2 | 3 | 4 |
| 1. Multidisciplinary (Integrated) care | 1 | 2 | 3 | 4 |
| 1. Psychological counseling service | 1 | 2 | 3 | 4 |
| 1. Mobility assistance service by taxis for disabled people and/or public transportation | 1 | 2 | 3 | 4 |