|  |
| --- |
| 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. | 1No assistance | 2Little assistance | 3Moderate assistance | 4Considerable 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. | 1No assistance | 2Little assistance | 3Moderate assistance | 4Considerable 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. | 1No assistance | 2Little assistance | 3Moderate assistance | 4Considerable 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 |