# ALSFRS-R-SE – the self-explanatory version of the Amyotrophic Lateral Sclerosis Functional Rating Scale – Revised

**ALSFRS-R-SE**
Version 2.1

*The ALSFRS-R-SE is an assessment of symptoms and motor deficits commonly associated with ALS that patients can complete themselves or with the help of others, such as a family member, caregiver, or healthcare professional, based on an interview with the patient.*

*Please carefully read the answer options and explanations. Then, select an option that reflects the current symptoms and motor functions compared to the situation before the onset of ALS.*

## 1. Speech

Please choose one of the following answers:

- ☐ 4 Normal
  *Speech is normal.*
- ☐ 3 Noticeable speech disturbance
  *Speech is slightly slurred or voice is rough, noticed by oneself or someone else.*
- ☐ 2 Repetition is needed for understanding
  *Speech is moderately slurred; sometimes words or parts of sentences need to be repeated to be understood.*
- ☐ 1 Speech combined with non-verbal communication
  *Speech is severely slurred; writing things down or use of communication aids are often needed to communicate.*
- ☐ 0 Loss of understandable speech
  *Speech is lost; writing things down, communication devices, or other supportive methods are always needed.*

## 2. Salivation

Please choose one of the following answers:

- ☐ 4 Normal
  *No excess saliva is accumulated in the mouth.*
- ☐ 3 Slight but definite excess saliva in the mouth. May have night time drooling
  *More saliva is kept in the mouth. Saliva may leak out at night, but not during the day.*
- ☐ 2 Moderate excess saliva. May have minimal day time drooling
  *A cloth or tissue is sometimes used to wipe the corners of the mouth.*
- ☐ 1 Marked excess saliva with some drooling
  *A cloth or tissue is often used, but not always.*
- ☐ 0 Severe excess saliva with marked drooling
  *A cloth or suction device is always required.*

## 3. Swallowing

Please choose one of the following answers:

- ☐ 4 Normal
  *Swallowing is normal.*
- ☐ 3 Minor swallowing difficulties and occasional choking
  *Eating takes more time, or smaller bites are taken and swallowed carefully. Occasional choking or more frequent coughing may occur.*
- ☐ 2 Moderate swallowing difficulties and dietary consistency changes
  *The texture of food and drinks is changed, or certain foods (e.g. meat, dry biscuits, nuts) are avoided. High-calorie drinks or thickening powders are used.*
- ☐ 1 Severe swallowing difficulties. Supplementary tube feeding
  *A feeding tube has been placed or recommended to maintain weight. Some food or drink can be taken by mouth.*
- ☐ 0 Unable to swallow. Exclusive tube feeding
  *A feeding tube has been placed. Eating or drinking by mouth is not possible.*

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**4. Handwriting**

*Comment: The subject of this assessment is writing with one's dominant hand (writing hand) in the usual posture.*

Please choose one of the following answers:

- ☐ 4 Normal
  *Writing is normal.*
- ☐ 3 Slow or sloppy but all words are legible
  *Writing is slower and less clear, but the words can be written.*
- ☐ 2 Not all words are legible
  *Some words are not legible. Tools may be used to make writing clearer.*
- ☐ 1 No words are legible, but can still grip pen
  *A pen can be held. Only the signature or one's own name, but no other words can be written.*
- ☐ 0 Cannot grip a pen
  *A pen cannot be held.*

**5. Use of a feeding tube**

☐ **No** For patients who do not use a feeding tube, **continue to 5a**

**OR**

☐ **Yes** For patients who use a feeding tube, **continue to 5b**

**5.a Cutting food and handling utensils**

Please choose one of the following answers:

- ☐ 4 Normal
  *Food is handled without difficulty using standard utensils such as a knife, spoon, fork, or chopsticks.*
- ☐ 3 Somewhat slow and clumsy, but no help needed
  *Food is handled more slowly or clumsily with standard utensils, but without help.*
- ☐ 2 Can cut most foods, although slowly and clumsily. Some help needed
  *Food can be handled independently, sometimes using special utensils such as adapted knives or forks. Help is occasionally needed to cut certain foods.*
- ☐ 1 Food must be cut by someone else. Can eat slowly on their own
  *Food can be handled independently, if needed using special utensils. Help is always needed to cut solid foods.*
- ☐ 0 Cannot eat on their own. Always help needed
  *Food cannot be handled independently. Help is always needed.*

**5.b Handling of feeding tube**

Please choose one of the following answers:

- ☐ 4 Normal
  *The feeding tube can be handled without difficulties.*
- ☐ 3 Somewhat slow and clumsy, but handling of feeding tube can be performed independently
  *The feeding tube is handled slowly or clumsily, but without help.*
- ☐ 2 Some help is needed when handling closures and lids
  *The feeding tube is handled independently, but help is needed with opening or closing some parts, such as caps or lids.*
- ☐ 1 Minimal assistance to care giver in the handling of feeding tube
  *The feeding tube cannot be handled independently. Help is mostly needed, and only small parts can be done alone.*
- ☐ 0 Unable to perform any aspects of the task
  *The feeding tube cannot be handled independently. Help is always needed.*

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**6. Dressing and hygiene**
Please choose one of the following answers:

☐ 4 Normal
*Dressing and hygiene are done without difficulties.*

☐ 3 Independent and complete self-care with effort or decreased efficiency
*Dressing and hygiene take longer but can be done without help.*

☐ 2 Intermittent help or substitute methods
*Dressing and hygiene are done with substitute methods, such as easy clothing or sitting while dressing. Help is sometimes needed.*

☐ 1 Needs help with self-care
*Dressing and hygiene cannot be done independently. Help is mostly needed, and only small parts can be done alone.*

☐ 0 Total dependence
*Dressing and hygiene cannot be done independently. Help is always needed.*

**7. Turning in bed and adjusting bed clothes**
Please choose one of the following answers:

☐ 4 Normal
*Turning in bed and handling blankets is normal.*

☐ 3 Somewhat slow and clumsy, but no help is needed
*Turning over in bed and handling the blankets are slower and clumsy, but without help.*

☐ 2 Can turn alone or adjust sheets, but with great difficulty
*Turning over in bed and handling the blankets can be done with great effort. Either action sometimes needs help.*

☐ 1 Can initiate, but not turn or adjust sheets alone
*Turning over in bed or handling the blankets can be started, but help is needed to complete them.*

☐ 0 Total dependence
*Turning over in bed and handling the blankets cannot be done independently. Help is always needed.*

**8. Walking**
Please choose one of the following answers:

☐ 4 Normal
*Walking is normal.*

☐ 3 Minor walking difficulties
*Walking is slower, feels steady, or leads to occasional tripping. No assistance is needed when outside.*

☐ 2 Walking with assistance
*Walking needs assistance, regularly when outside, either by holding onto support by using a foot lifter or walking aid, or with help from someone else.*

☐ 1 Unable to walk. Non-ambulatory leg movement
*Walking is not possible, even with walking aids or the help of someone else. Standing is possible with assistance, for example when transferring from bed to chair. The legs can be moved purposefully.*

☐ 0 Unable to walk. No purposeful leg movement
*Standing is not possible, even with assistance. The legs cannot be moved purposefully.*

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**9. Climbing the stairs**

Please choose one of the following answers:

- ☐ 4 Normal
  *Climbing the stairs is normal.*
- ☐ 3 Slow
  *Climbing the stairs is slowed but steady.*
- ☐ 2 Mild unsteadiness or fatigue
  *Climbing the stairs is slowed and unsteady, and rest may be needed. Assistance, such as holding a handrail, is not regularly required.*
- ☐ 1 Needs assistance
  *Climbing the stairs requires assistance, such as a handrail or help from someone else.*
- ☐ 0 Cannot climb
  *Climbing the stairs is not possible, even with help.*

**10. Shortness of breath**

Please choose one of the following answers:

- ☐ 4 No breathing difficulty
  *No shortness of breath is felt when doing daily activities.*
- ☐ 3 Occurs when walking
  *Shortness of breath is felt when walking at a normal speed or doing everyday tasks that need some effort.*
- ☐ 2 Occurs with one or more of the following: eating, bathing, dressing, prolonged speaking
  *Shortness of breath is felt during light activities.*
- ☐ 1 Difficulty breathing when at rest, including either sitting or lying down
  *Shortness of breath is felt when resting, such as sitting or lying down.*
- ☐ 0 Significant difficulty breathing, mechanical respiratory support may be needed
  *Intense shortness of breath is felt when resting. Ventilation support, such as a breathing mask or tracheostomy, is needed.*

**11. Sleep disturbance due to shortness of breath**

*Comment: If a breathing mask is used at night but sleep is also possible without it, sleep should be rated for nights without the mask.*

Please choose one of the following answers:

- ☐ 4 None
  *Sleep is not disturbed due to shortness of breath.*
- ☐ 3 Some difficulty sleeping at night due to shortness of breath. More than two pillows are not routinely used
  *Sleep is disturbed due to shortness of breath. Sleeping on the side improves the breathing.*
- ☐ 2 Regular use of more than two pillows required for sleeping
  *Sleep is difficult due to shortness of breath. Sleeping with three or more pillows or by raising the head of the bed improves the breathing.*
- ☐ 1 Can only sleep sitting up
  *Sleep is possible only when sitting up, either in bed or in a chair.*
- ☐ 0 Unable to sleep
  *Sleep is possible only with ventilation support such as breathing mask or tracheostomy.*

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**12. Ventilation support, such as a breathing mask or tracheostomy**

Please choose one of the following answers:

☐ 4 None

*No ventilation support is used. An existing treatment of sleep apnoea with a CPAP mask is not counted as ventilation support.*

☐ 3 Intermittent use of breathing mask

*A breathing mask is used not every night or not throughout the entire night.*

☐ 2 Continuous use of breathing mask during the night

*A breathing mask is used every night and sometimes during the day, for a total of 8 to 22 hours.*

☐ 1 Continuous use of non-invasive ventilation during the night and day

*A breathing mask is used nearly all night and day, for more than 22 hours.*

☐ 0 Invasive ventilation with tracheostomy

*Invasive ventilation is used through a tracheostomy.*