

KNOWLEDGE IS POWER...

ALS FUNCTIONAL RATING SCALE REVISED (ALSFRS-R)

Attending an ALS Clinic either face to face or virtually, can be overwhelming. Taking part in a Clinical Trial can be equally as overwhelming. Why are they checking this, what does this question mean, can they tell if my disease is progressing and how quickly? All these questions should be directed to your healthcare provider, but one common feature you may encounter is the ALS Functional Rating Score, in use since the early 1990's in its original form and in its revised form since 1999.

The ALSFRS-R, originally designed to objectively (based on observable facts rather than feelings or opinions) measure any change in a person's health after a period of treatment during clinical trials in ALS. ALSFRS-R is now used in both ALS Research and in clinical practice to establish baseline disease severity at diagnosis and to assess disease progression over time. The assessment can be performed by a healthcare provider or by a PALS using a self-administered form. More severe or lower ALSFRS-R scores may encourage earlier discussions between PALS and healthcare providers around provision of respiratory support, PEG (feeding tube), dietary changes or even end of life care.

It is important to realize that every person with ALS is an individual and an ALSFRS-R needs to be carefully interpreted considering the individual's disease course and duration. Every score is personal and even if the scores of two PALS are exactly the same, their symptoms could be wildly different.

What exactly is measured in the ALSFRS-R and how is the score interpreted? There are twelve elements or variables, and for each variable the score ranges from 0 to 4, with 4 being the best possible measurement. The maximum score is 48 points. Scores lower than 48 must be carefully interpreted.

Variables assessed include:

- Speech
- Salivation
- Swallowing
- Handwriting
- Cutting food and handling utensils (for persons using a PEG for primary nutrition, ability to personally perform functions necessary to use the PEG)
- Dressing and hygiene
- Turning in bed and adjusting bed clothes
- Walking