CDR® plus NACC FTLD-NM

The ***CDR®+NACC-FTLD-NM*** is a clinical rating scale that includes the standard CDR, the addition of the NACC FTLD module, and the further addition of the NM module i.e. two other domains: N for neuropsychiatric symptoms and M for motor symptoms.

Initially complete the **CDR** as per the standard methodology: https://knightadrc.wustl.edu/professionals-clinicians/cdr-dementia-staging-instrument/. Then complete the **NACC FTLD (behaviour and language) module** as per the standard methodology https://www.naccdata.org/collect-and-submit-nacc-data/data-collection-training/#administering-the-ftld-module.

The **Neuropsychiatric and Motor domains** can be assessed through considering the following symptoms in each domain and then giving an overall score for each domain (shaded area) which contributes to the final CDR®+NACC-FTLD-NM. The scales should be assessed through a combination of participant and informant histories as well as observation and assessment by the clinical team.

Neuropsychiatric symptoms

		Absent	Questionable/ Very mild	Mild	Moderate	Severe
	Neuropsychiatric	□ 0	□ 0.5	□ 1	□ 2	□ 3
A	**Hallucinations** Sees, hears or feels things that are not there	□ 0	□ 0.5	□ 1	□ 2	□ 3
B	**Delusions** Paranoia, fear of harm, fear of theft, fear of abandonment, delusional misidentification	□ 0	□ 0.5	□ 1	□ 2	□ 3

SCORING GUIDANCE:		**Questionable/ Very mild**	**Mild**	**Moderate**	**Severe**
	Neuropsychiatric	Questionable neuropsychiatric symptoms.	Mild but definite neuropsychiatric symptoms.	Moderate neuropsychiatric symptoms.	Severe neuropsychiatric symptoms.
A	**Hallucinations** Sees, hears or feels things that are not there	Some hallucinations may have occurred but are of questionable significance	Hallucinations are present but harmless and cause little distress for the patient.	Hallucinations are distressing and are disruptive to the patient.	Hallucinations are very disruptive and a major source of behavioural disturbance. PRN medications may be required to control them.
B	**Delusions** Paranoia, fear of harm, fear of theft, fear of abandonment, delusional misidentification	Some delusions may have occurred but are of questionable significance.	Delusions present but seem harmless and produce little distress in the patient.	Delusions are distressing and disruptive.	Delusions are very disruptive and are a major source of behavioural disruption. If PRN medications are prescribed, their use signals marked severity.

Participant ID		**Visit number**		**Visit date/month/year**			

Motor symptoms

		Absent	Questionable/ Very mild	Mild	Moderate	Severe
	Motor	□ 0	□ 0.5	□ 1	□ 2	□ 3
A	**Dysarthria** Has the person had difficulties with articulation?	□ 0	□ 0.5	□ 1	□ 2	□ 3
B	**Dysphagia** Has the person had difficulties with swallowing?	□ 0	□ 0.5	□ 1	□ 2	□ 3
C	**Tremor** Has the person had rhythmic shaking, especially in the hands, arms, legs or head?	□ 0	□ 0.5	□ 1	□ 2	□ 3
D	**Slowness** Has the person slowed down in walking, moving or handwriting, other than injury or illness? Has the subject's facial expression changed or become more unexpressive?	□ 0	□ 0.5	□ 1	□ 2	□ 3
E	**Weakness** Has the person noticed their arms or legs have become weak?	□ 0	□ 0.5	□ 1	□ 2	□ 3
F	**Gait disorder** Has the person's walking changed, not specifically due to arthritis or injury? Is the subject unsteady, or shuffle when walking, or drag a foot?	□ 0	□ 0.5	□ 1	□ 2	□ 3
G	**Falls** Does the person fall more than usual?	□ 0	□ 0.5	□ 1	□ 2	□ 3
H	**Functional difficulties using hands** E.g. using knife and fork, buttoning clothes, washing hands and face	□ 0	□ 0.5	□ 1	□ 2	□ 3
I	**Cramps** Has the person had muscle cramps in the arms or legs?	□ 0	□ 0.5	□ 1	□ 2	□ 3

SCORING GUIDANCE:		**Questionable/ Very mild**	**Mild**	**Moderate**	**Severe**
	Motor	Questionable/very mild motor impairment.	Mild motor impairment.	Moderate motor impairment.	Severe motor impairment.
A	**Dysarthria** Has the person had difficulties with articulation?	Possible speech disturbance of questionable significance or very mild.	Detectable speech disturbance – may be asked to repeat statements infrequently.	Becoming less intelligible – frequently asked to repeat statements.	Generally unintelligible.
B	**Dysphagia** Has the person had difficulties with swallowing?	Rare choking of questionable significance.	Swallowing problems are evident with regular episodes of choking.	Requires changes in dietary consistency.	Needs supplemental tube feeding.

Participant ID		Visit number		Visit date/month/year			

C	**Tremor** Has the person had rhythmic shaking, especially in the hands, arms, legs or head?	Tremor is infrequently present and of questionable significance or very mild.	Tremor is evident but is generally not distressing to the patient.	Tremor is evident, may be distressing and interferes with many activities.	Tremor interferes with most activities.
D	**Slowness** Has the person noticeably slowed down in walking or moving or handwriting, other than injury or illness? Has the subject's facial expression changed?	Slight slowing down of movements of questionable significance or very mild.	Mild slowing – slower walking but requires little or no assistance; writing slower but still legible; definite diminution of facial expression.	Moderate slowing – walks with assistance; not all words legible when writing; lips parted some of the time.	Severe slowing – cannot walk; majority of words not legible; severe or complete loss of facial expression.
E	**Weakness** Has the person noticed their arms or legs have become weak?	Possible weakness of limbs but of questionable significance or very mild.	Mild weakness – does not require assistance with using arms or walking.	Moderate weakness – requires assistance walking or with activities requiring the arms.	Severe weakness – unable to walk and/or use arms.
F	**Gait disorder** Has the person's walking changed, not specifically due to arthritis or injury? Is the subject unsteady, or shuffle when walking, or drag a foot?	Possibly some difficulties with walking but of questionable significance or very mild.	Requires little or no assistance.	Walks with assistance.	Cannot walk at all, even with assistance.
G	**Falls** Does the person fall more than usual?	Rare falls of questionable significance.	Occasional falls but less than once per day.	Falls on average once daily.	Falls more than once daily.
H	**Functional difficulties using hands** E.g. using knife and fork, buttoning clothes, washing hands and face	Possible functional difficulties using hands but of questionable significance or very mild.	Requires little or no assistance.	Requires assistance.	Cannot use hands at all even with assistance.
I	**Cramps** Has the person had muscle cramps in the arms or legs?	Cramps are infrequently present and of questionable significance or very mild.	Cramps are evident but are generally not distressing to the patient.	Cramps are evident, may be distressing and interfere with many activities.	Cramps interferes with most activities.

Participant ID		Visit number		Visit date/month/year			

Scoring

A ***CDR®+NACC-FTLD-NM Sum Of Boxes (SOB) score*** can be scored by adding the overall Neuropsychiatric and overall Motor score (shaded regions) to the CDR®+NACC-FTLD score.

A ***CDR®+NACC-FTLD-NM Global score*** can be scored using the following algorithm:

1. If **all domains are 0**, the global FTLD-CDR score is 0.
2. If the **maximum domain score is 0.5**, the global FTLD-CDR score is 0.5.
3. If the **maximum domain score is above 0.5 in any domain**, then the following applies:
    a. If the maximum domain score is 1 and all other domains are 0, the global FTLD-CDR score is 0.5.
    b. If the maximum domain score is 2 or 3 and all other domains are 0, the global FTLD-CDR score is 1.
    c. If the maximum domain score occurs only once, and there is another rating besides zero, the global FTLD-CDR score is one level lower than the level corresponding to maximum impairment (e.g. if maximum = 2, and there is another rating besides zero, the global FTLD-CDR score is 1; if maximum = 1, and there is another rating besides zero, the global FTLD-CDR score is 0.5).
4. If the maximum domain score occurs more than once (e.g. 1 in 2 domains, 2 in 2 domains), then the global FTLD-CDR score is that maximum domain score.