

Frontotemporal Dementia Rating Scale FRS

Scoring guide

This guide was designed to help with scoring of the FRS. Bear in mind that the scoring should be done in comparison to the patient's pre-morbid functioning. Some examples are provided to help in the scoring.

BEHAVIOUR

1. Lacks interest in doing things - their leisure activities, own interests

Never: patient does not require prompting to do own leisure activities; is generally interested in taking part in the activities they are currently capable of doing. Might even have started new activities after retiring.

Sometimes: patient needs some prompting for some activities that they did not need before

All the time: apathy has affected their ability to initiate most activities, even if they can still initiate one or two activities on their own

2. Lacks normal affection, lacks interest in family members worries

Never: patient does not show changes in their affection towards family members or family concerns

Sometimes: patient is less affectionate to spouse or family members; shows less interest in family concerns

All the time: patient is oblivious to family concerns; marked lack of affection

3. Is uncooperative when asked to do something

Note: this does not include problems complying with requests due to disorganised behaviour or language comprehension deficits. If the patient is still willing to attempt the request, but fails due to cognitive problems, then score "never"

Never: patient cooperates with activities to the same level as before the disease onset

Sometimes: patient is less cooperative when asked to do things, or might refuse help at times

All the time: patient does not cooperate with others

4. Disorientation in unusual surroundings

Never: patient is able to orientate themselves in unfamiliar areas

Sometimes: patient might be confused in unfamiliar areas, but not much more than pre-morbidly

All the time: patient is always confused in unfamiliar areas (even if is still orientated in familiar places)

5. Is restless

Never: no changes

Sometimes: patient is restless sometimes

All the time: patient is pacing around the house, or rummaging cupboards; fidgeting or constantly moving legs

6. Acts impulsively without thinking

Never: no changes

Sometimes: presents with impulsive behaviour sometimes

All the time: patient does or says things that are embarrassing to family members, which they did not use to do before (e.g. making comments of people's weight; approaching strangers for a chat as if they were friends) **OR** patient might do dangerous things without proper judgement (e.g. trying to get out of the car while it is in motion; tries to climb the roof to fix the antenna when is clearly not able to do so)

7. Forgets what day it is

Never: no changes; patient follows correct routine for each day without prompting; informant shows no concern in patient's ability to follow appointments

Sometimes: patient sometimes forgets which day it is;

All the time: patient is disorientated in time most of the time, or all the time

OUTING AND SHOPPING

8. Has problems taking his/her usual transportation safely

(Car if pre-morbidly had a driver's licence; bike or public transport if did not have a driver's licence. Rating based on pre-morbid level. Does not include modifications made to cater for physical disability)

Never: no changes

Sometimes: informant might have noticed some subtle changes in driving; cannot say for sure what seems wrong. If patient was not a driver previously: patient might have trouble with bus routes, or taking the train on more than one occasion.

All the time: patient does not drive any longer; or still drives with a restricted licence. Patient does not drive any longer but still takes public transport. Patient does not take public transport any longer

9. Has difficulties shopping on their own

(Rating based on pre-morbid level. For instance, if they used to do the big weekly shopping but now can only do a small shopping at the local shops, score this as "All the time". Or if they only used to get a few items from the local shop, score based on this level)

Never: no changes. Can independently do the grocery shopping (if used to) or small shopping (if used to).

Sometimes: patient might have started needing extra aids, such as using a shopping list, which was previously not required; patient may come away with only some of the intended items. A one-off occasion of problems while shopping that seems out of character is scored under "never".

All the time: patient cannot do the shopping without help, or might still be able to do the small shopping BUT used to do the main weekly shopping. Patient does not go shopping any longer.

HOUSEHOLD CHORES AND TELEPHONE

Ascertain first if the patient was the main person looking after the house. If the patient used to do only a couple of tasks, rate their ability to perform those (questions 10 and 11).

10. Lacks interest or motivation to perform household chores that he/she used to perform in the past

(Rate based on pre-morbid level)

Never: no changes.

Sometimes: patient needs occasional prompting (do not underscore performance if patient always needed an occasional prompting. If patient used to be prompted pre-morbidly, then score N/A for question 10).

All the time: patient does not take initiative to do house chores as they used in the past. Patient used to do all house chores independently but now only does a few without prompting. Patient might still do tasks if asked/prompted/pushed to.

11. Has difficulties completing household chores adequately that he/she used to perform in the past

(This does not include changes in quality caused by physical disability)

Never: no changes.

Sometimes: occasional problem in executing tasks; occasional lack of quality if compared to previous performance.

All the time: patient might still do the chores but not to the same standard (e.g. rooms are not sparkling clean as before; dishes need to be re-washed; table is set wrongly). Patient does not execute them even if asked.

12. Has difficulty finding and dialling a telephone number correctly

Never: no changes.

Sometimes: occasional need for help; is only able to dial people from pre-programmed buttons on the telephone

All the time: patient needs help when finding and dialling a number; patient does not use the telephone any longer.

FINANCES AND CORRESPONDENCE

Ascertain first if the patient used to be responsible to the finances of the household before symptom onset. If so, carry out questions regarding finances. If not, still address question 13 but tick N/A for question 14.

Managing correspondence is addressed in question 15, and the underlying function we are evaluating is language skills (writing and/or comprehension). As there is a hierarchy of abilities in managing finances, if patient clearly organises all bills, payments and investments to a high level, question 16 can be answered based on previous 3 questions.

13. Lacks interest in his/her personal affairs such as finances

Never: no changes.

Sometimes: patient might still look at the bank statements that arrive but does not initiate any action needed.

All the time: patient is not interested if there is enough money available, or how finances are going. Patient used to be the “manager” of the finances, but now lost interest completely.

14. Has problems organising his/her finances and to pay bills

(cheques, statements, bills)

Never: no changes.

Sometimes: patient needs occasional help.

All the time: patient cannot organise bills/payments/investments without help. Patient does not do any financial transactions any longer.

15. Has difficulties organising his/her correspondence without help

(writing/ reading skills)

Never: no changes.

Sometimes: patient still deals with letters/emails but sometimes asks spouse/family members to check spelling, etc.

All the time: patient does not write letters/emails without help, or might have stopped writing.

16. Has problems adequately handling cash in shops, petrol stations, etc

(give and check change; note this item is more about ability to understand and use cash than the physical skills or holding and manipulating coins)

Never: no changes.

Sometimes: might have problems using cash occasionally.

All the time: patient has difficulties paying by cash; might prefer paying by card or uses only bigger notes. Does not check change, does not understand the value of bank notes or coins, or does not use cash any longer.

MEDICATIONS

In this section we evaluate whether the patient just needs a prompt (and knows the doses), if they need to have medication doses prepared (but remembers to take them), or both. Rate based on pre-morbid level (e.g. if patient used to have the medications prepared by the spouse for the last 20 years, score N/A)

17. Has problems taking his/her medications at the correct time

(forgets or refuses to take them)

Never: no changes.

Sometimes: patient needs occasional prompting to take medication (clearly more than pre-morbidly). A one-off occasion that seems out of character is scored under "never".

All the time: patient does not take medications without prompting, or medication is given to them. Patient might know the dose but does not to take the medication at the correct time.

18. Has difficulties taking his/her medications as prescribed (according to the right dosage)

Never: no changes.

Sometimes: patient needs occasional help in sorting out medication doses.

All the time: patient might take medication from the pillbox/Webster packs without prompting but would not know how many tablets are prescribed (follows the days of the week from the pillbox or Webster packs). Medication is given to them.

MEAL PREPARATION AND EATING

Ascertain first if patient used to be the main cook in the house, an occasional helper, or did not use to prepare any meals. In this section we evaluate whether the patient needs help to prepare a full meal (if used to be the main cook), **or** breakfast/light snack (e.g. used to prepare a sandwich for themselves but was never responsible for meal preparation). The scoring for questions 19, 20 and 21 should be based on the **same** task, e.g. preparing a meal, or preparing a sandwich. Do not start rating one task for initiation and then switch to another task for execution.

19. Lacks previous interest or motivation to prepare a meal (sandwich, or a light meal) or snack for himself/herself

Never: no changes.

Sometimes: patient needs occasional prompt to carry out a meal preparation/snack when did not use to need before.

All the time: patient will only do the task if asked; needs prompt most of the time; patient used to do main meals but now can only prepare a light snack/sandwich

20. Has difficulties organising the preparation of light meals or snacks

(ingredients, cookware, sequence of steps)

Never: no changes

Sometimes: patient needs occasional help with planning (does not know where ingredients are, or which should be used, or in which order the preparation should happen)

All the time: patient cannot prepare a meal or a snack without help in the organisation process. Carer might lay out all ingredients for the patient to prepare a sandwich, for instance.

21. Has problems preparing or cooking a light meal or snack on their own
(needs supervision/help in kitchen)

Never: no changes.

Sometimes: patient needs occasional help. A one-off occasion that seems out of character is scored under "never", e.g. forgot the stove on ONCE. Patient might have bought a new microwave and struggled to use it a few times.

All the time: patient cannot cook on their own (somebody is often overseeing for safety reasons; or patient cannot execute parts of the task because of lack of strength or apraxia). Patient might be at risk if left on their own.

22. Lacks initiative to eat

(if not offered food, might spend the day without eating anything)

Never: no changes; will go and get food from the cupboard or fridge if hungry.

Sometimes: patient needs occasional prompt.

All the time: patient does not eat unless food is offered directly, or is obviously at sight.

23. Has difficulties using and choosing appropriate utensils when eating

Never: no changes.

Sometimes: patient needs occasional help (clearly more often than pre-morbidly). A one-off occasion that seems out of character is scored under "never". Patient was very skilled at using different types of cutlery but is now muddled with them.

All the time: patient uses serving spoon to eat own meal; gets confused between fork and knife most of the time; patient has sections of their meal cut up for them so that they do not need to use both knife and fork

24. Has problems eating meals at a normal pace and with appropriate manners

Note, this item does not include changes in eating due to dysphagia

Never: no changes.

Sometimes: patient might have had problems with manners on some occasions. A one-off occasion that seems out of character is scored under "never".

All the time: patient eats too fast (might put too much food in mouth); patient eats too slowly (might drop food on table, floor). Patient might take food from others; patient might serve too much food for themselves even if there are other guests at the table.

25. Wants to eat the same foods repeatedly

Note, this item does not include changes in eating due to dysphagia (if a patient's diet has become more restricted as a result of difficulty eating certain foods)

Never: no changes, e.g. eats a variety of foods.

Sometimes: patient might have preferences on occasion, e.g. Christmas sweets at Christmas time.

All the time: patient wants to eat same foods for weeks; might change to another type of food for another number of weeks. Fixed on certain foods, or always adds a certain type of sauce/seasoning to the food.

26. Prefers sweet foods more than before

Never: no changes.

Sometimes: patient has preferences on occasion.

All the time: patient now prefers cakes, sweets, chocolates, soft drinks etc. Might eat sweets at dinner time. Or always adds a certain type of sweetener to the food (e.g. patient adds cranberry sauce to savoury and sweet dishes to make them all sweet).

SELF CARE AND MOBILITY

In this section we evaluate basic abilities. If patient has scored "never" for most of the questions above, patients will likely score "never" in these 4 remaining questions. Question 30 is scored by observation.

27. Has problems **choosing** appropriate clothing
(with regard to the occasion, the weather or colour combination)

N/A: the spouse always laid out the clothes for the patient

Never: no changes.

Sometimes: patient needed help on some occasions, which was clearly more than they used to need. If the patient used to ask for the spouse's opinion when choosing clothes and still does (habit), score "never".

All the time: patient might want to always wear the same clothes (even if they are dirty or even if they are going out). Patient might make strange combinations (e.g. sports socks and a cocktail dress) or overdress for an informal occasion.

28. Is **incontinent**

(not including functional incontinence, where mobility problems restricts the ability to get to the toilet on time)

Never: no changes; patient retains bladder control

Sometimes: patient needs occasional prompt (clearly more often than pre-morbidly). A one-off occasion of wetting oneself that seems out of character is scored under "never".

All the time: patient uses an adult diaper/nappy/pad regularly during day or night.

29. Cannot **be left** at home by himself/herself for a whole day
(for safety reasons)

Never: no changes.

Sometimes: carer leaves patient alone but has to call several times in the day to prompt patient, or check how they are doing

All the time: carer might leave patient alone for a couple of hours only

30. Is restricted to the **bed**

Never: patient is ambulant

All the time: patient is bed-ridden
