

# Frontotemporal Dementia Rating Scale FRS

## Interview guide

### BEHAVIOUR

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

- Which are --- leisure activities?
- Does --- need prompting to do his leisure/hobbies activities?

(Is there a decrease in interest? If informant says patient never had leisure activities before check if they might have had interest in sports on TV, films on TV, reading, etc. Note sometimes there are changes in leisure activities due to physical disability – here, the aim is to evaluate level of interest. If activities have declined due to inability to engage in them, prompt for level of interest in what the patient is still able to do)

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

- How is --- in demonstrating affection?
- Is he/she affectionate to you, or their children?
- Does he/she seem concerned about their children/parents?

#### 3. Is uncooperative when asked to do something

- When you ask --- to do something, does he/she normally agree or try to do as you asked?
- Is he/she difficult to deal with?
- If patient is quite impaired, ask if they refuse help

#### 4. Becomes confused or muddled in unusual surroundings

- When --- goes out, is he/she generally good at finding their bearings?
- If you went to a different shopping centre or visited a friend you don't see often, would he/she be ok making his/her way around? Would they be able to find the car again?
- Is it better when it is a familiar place?
- Has he/she been ever good at orientating themselves – where home is, where the shops are, north/south, etc?

#### 5. Is restless

- Does --- rummage around the house all the time?
- Is he/she fidgeting all the time? Or moving their legs, for instance?  
(Informant might mention that patient cannot sit still while watching TV, or patient is pacing all the time)

#### 6. Acts impulsively without thinking

- Does --- say or do things in public that might be embarrassing to you or to your children?
- Does he/she make comments that might be rude to other people?
- Does he/she approach strange people and talk as if they were friends?
- Does he/she make rash decisions (e.g. with spending money)?
- Have you been concerned about his/her safety when doing activities because they may not be thought through?

## 7. Forgets what day it is

- Does --- keep track of which day it is, or if it is the weekend?
- Does --- use a calendar, or a diary?
- Does he/she normally know the appointments of the day/week?
- Do you need to prompt him/her about the appointments of the day?

## OUTING AND SHOPPING

### 8. Has problems taking his/her usual transportation safely

(car if has a driver licence; bike or public transport if does not have a driver licence)

- Does --- drive? Did he/she use to drive? (if never driven evaluate ability to take public transport, or ride their bicycles if applicable)
- Does he/she take the bus/train on their own?

### 9. Has difficulties shopping on their own

(e.g. to go to the local shops to get milk and bread)

Ascertain previous level of shopping to determine whether patient can still perform to the same level..

- Does --- do the grocery shopping?
- Does --- buy bread and milk at the local shop when needed?
- Does --- normally bring home what they had planned/were asked to?
- Do they use a shopping list now? Did they used to?
- How do they pay: by credit card, cash? (this question can be used later for determining ability in the finances section)

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## HOUSEHOLD CHORES AND TELEPHONE

Ascertain if patient was the main person looking after the house, or somebody who had only a couple of tasks to do

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

- If female: does --- look after the house like in the past?
- Does she need more help than she used to?
- Does she need **prompting** to do those tasks?
- If male: which activities does --- do in the house?
- Is there an activity he has always done (e.g. ironing; taking rubbish out; mowing the lawn)?
- Does he need **prompting** to do those tasks?

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

- When she/he does that task, does he/she do a good job?
- Do you need to re-do them later?

### 12. Has difficulty finding and dialling a telephone number correctly

Bear in mind that patients with Semantic Dementia or PNFA might have trouble using the phone due to language difficulties, but no difficulty in finding and dialling a number – as seen in patients with Alzheimer's disease.

- Does he/she use the telephone?
- Does he/she avoid answering the phone?

- Does he/she make calls?

## 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 skip 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 and may not need to be probed separately.

### 13. Lacks interest in his/her personal affairs such as finances and written correspondence

- Does he/she used to look after the finances? If yes:
- Is he/she doing that at the moment? (e.g. paying bills, keeping track of statements, making investments) Does he/she need some help from you?
- If answer is no: Is he/she still interested in knowing how the finances are going?

### 14. Has problems organising his/her finances and to pay bills (cheques, bankbook, bills)

- Is he/she doing that at the moment? (e.g. paying bills, keeping track of statements, making investments) Does he/she need some help from you/somebody?
- (informant might have answered this above)

### 15. Has difficulties organising his/her correspondence without help (writing skills)

- Does he/she deal with letters/emails that need to be replied?
- Does he/she need help with spelling, checking what was written?

### 16. Has problems handling adequately cash in shops, petrol stations, etc (give and check change)

- Does he/she normally pay for shopping, or a coffee with cash or card (credit or debit?)
- Does he/she understand the value of the bills?
- Does he/she pay with one large bill to avoid calculating?
- Is he/she able to check change given and know if it's correct?

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## MEDICATIONS

### 17. Has problems taking his/her medications at the correct time (forgets or refuses to take them)

- Does he/she take any medication at the moment? If no, mark N/A. If yes:
- Does he/she need any prompting to take the medication at the correct time?

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

- Does he/she know how many tablets/pills they should take?
- Does he/she use a pill box or Webster packs? If yes, who prepares them?

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## 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 probes for questions 19, 20 and 21 should be based on the **same** task, e.g. preparing a meal, or preparing a sandwich, rather than asking about one task for initiation and then switch to another task for execution.

### 19. Lacks previous interest or motivation to prepare a meal (or breakfast/ sandwich if did not use to cook) or snack for himself/herself

Ascertain previous level of cooking and then score whether patient can still perform to the same level.

- Does he/she prepare something to eat? (e.g. full meal if used to be the main cook, or light snack such as sandwich, toast, for less proficient cooks)
- Does he/she need you to prompt them to prepare?
- If patient does not prepare things to eat and never did, go to Q22

### 20. Has difficulties organising the preparation of light meals or snacks (ingredients, cookware, sequence of steps)

- Does he/she need help while preparing the meal/snacks?
- Have they simplified their cooking style (less complex meals)?

### 21. Has problems preparing or cooking a light meal or snack safely (needs supervision in kitchen)

- Does somebody need to be there while they are cooking?
- Do they leave the stove on?
- Do they handle the knives well?

### 22. Lacks initiative to eat

(if not told to, might spend the day without eating anything)

- When he/she is hungry, does he get something to eat? (e.g. a piece of fruit, a snack)
- Does he/she rely on you to bring something for them to eat?

### 23. Has difficulties choosing appropriate utensils when eating

- Does he/she use the cutlery like they used to use before?
- Any problems with fork or knife?

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

- Is he/she eating too fast or too slow now?
- Is he/she putting too much food in the mouth?
- Is he/she now a messier eater?

### 25. Wants to eat the same foods repeatedly

- Does he/she have any favourite foods that he/she has to have most of the time?
- Which foods are those? (if sweets, score also question 26)

### 26. Prefers sweet foods more than before

- Make sure the patient did not already have a sweet tooth prior to disease onset

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## SELF CARE AND MOBILITY

### 27. Has problems choosing appropriate clothing

(with regard to the occasion, the weather or colour combination)

Ascertain if the spouse might have always laid out the clothes for the patient for the last 20 years. In this situation, score N/A and go to Q28

- When he/she is getting ready for the day, does he/she need help in choosing their clothes?
- Does he/she always want to wear the same clothes (even if they are dirty)?

### 28. Is incontinent

- Be aware of carers' sensitivity to this question. If patient scored never for most of the questions above, it is highly likely they will score never for question 28 as well.
- Does he/she have problems going to the toilet?
- Has he/she ever had an "accident" when going to the toilet?

### 29. Cannot be left at home by himself/herself for a whole day

(for safety reasons)

- Be aware of carers' sensitivity to this question. If patient scored never for most of the questions above, it is highly likely they will score never for question 29 as well.
- Are there times when you go out and he/she stays at home by themselves?
- For how long do they normally stay at home alone?

### 30. Is restricted to the bed

- This question does not need asking and can be scored upon observation.
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