

SF-DEM: Social Functioning in Dementia scale - Manual

Person with dementia- and carer-rated instruments for assessing social functioning in dementia

Instructions for interviewer

Preparation

- The instruments are designed to be used for a person with dementia and/or for their carer (unpaid, main carer, who would usually be a relative or friend).
 - The patient-rated version has been validated in people with mild dementia (MMSE>20) but may be less accurate in people with more severe dementia (Sommerlad et al 2017).
 - The carer-rated version has been validated in people with dementia of any severity (Budgett et al 2019).
- The instruments should be administered to participants separately (i.e. do not interview the person with dementia and their carer simultaneously).
- You will need a copy of the SF-DEM instrument for each participant. Please note there are slight differences between wording of questions to be directed to for the person with dementia and the carer.
- Explain that you are going to ask questions about social aspects of their life, such as hobbies, interests and relationships and ensure that the respondent is happy to answer.
- Read the opening statement (in bold type) verbatim and then give the prompt card to the respondent, while explaining the definition for each response.

Assessing ability to answer questions

- There are no practice questions. If the respondent struggles to give an answer to the first three questions, despite prompts outlined in the next section, then stop and record the reasons.

Administering the questionnaire items

- Read each item exactly as written. For each item, read the stem part of the question, i.e. *'Thinking about the past month, how often have you...'*.
- If participants struggle to choose one option, please prompt them to pick from the prompt card, and remind them of the definitions of each category. If still unable (e.g. respondent says 'between occasionally and never'), then you should mark the more frequent option.

SF-DEM should be marked with careful interpretation of the participants' response

- Participants may not recall the specific definitions of each response category (very often, often, occasionally, never). You may remind them while pointing to the prompt card. However, they do not need to give a specific answer and you can mark SF-DEM based on their response.

- A participant may give an immediate answer using one of the categories, and it is important to clarify that they understand what is meant by that category. Therefore, please briefly enquire as to the frequency of the activity or behaviour. Unless the respondent has demonstrated good understanding of each category, clarify their meaning before marking the instrument.
- You can derive the correct response from brief dialogue. Examples of respondent answer and approaches for interviewer to clarify respondent are in *figure 1*.

Figure 1: Examples of respondent answer and potential interviewer response

Question	Participant comment	Category	Interviewer response
1	‘My son visits me every day after work’	Very often	‘That fits into the <i>very often</i> category, so I will mark that.’
6	‘I go to a cafe once a week and to the pub about once per month’	Often	‘I will mark that as <i>often</i> , seeing as you do that about once a week.’
4	Respondent answers, ‘Very often’ Interviewer would ask, ‘Do you mean that you go shopping with someone else every single day, or is it less often than that?’ If respondent says, ‘Yes my wife and I go out to the shops daily’, interviewer would mark <i>very often</i> . If respondent says, ‘No we don’t go out every day, but we go out at least a couple of times a week’, interviewer would mark <i>often</i> and clarify to the respondent, ‘OK, that fits in our categories as <i>often</i> so I will mark that.’		

Other activities

- The list of activities in questions 3-7 is not exhaustive. If participants volunteer a different social activity which they do with others which is not listed in SF-DEM, you should fit this into one of SF-DEM’s categories (*figure 2* for examples).
- You should maximise the participants’ score based on their answers, so if a participant is in a choir which meets weekly and also attends church weekly, you would mark question 3 as *often* (church) and question 6 as *often* (choir). If a participant goes shopping and goes to a café twice per month, you should mark 4 and 6 as *occasionally*.
- You should not score twice for the same activity (e.g. if one activity fulfils two roles).

Possible queries and responses

- For questions 3-7, participants may report a social activity which does not fit the question you have asked, but addresses a later domain. You could tell the participant ‘that option answers another of my questions, so I’ll ask you about that later on.’ Then repeat the original question.

Figure 2: Alternative activity options

Question	SF-DEM	Options
1	Seen friends or family in own home	Includes contact with any relative / friend / acquaintance who cohabits or visits the person with dementia (not including paid carers).
3	Attending community or religious meetings	Going to church services or groups / mosque / synagogue / temple etc. Going to neighbourhood watch meetings or local political meetings.
4	Gone shopping with friends and family	Can both be purchasing, shopping, online shopping, e.g., clothing or groceries together with friends or acquaintances or family
5	Gone on trips or to events like cinema or talks	Day trips to places like landmarks, historic sites. Visiting museums or galleries. Going to the theatre.
6	Gone to a café, restaurant, pub or social club	Day centre or lunch club also acceptable.
7	Exercised, walked or played sport with others	Includes day centre.
3-7		Includes activities with co-habiting family
9	Started or taken part in a conversation	The person with dementia should have initiated the conversation or had lengthy/meaningful conversation.
10/11	Talked to others about your feelings or concerns Asked others about their feelings or concerns	The person with dementia should have engaged with conversation about their or others' feelings to ask for or offer advice or support. It should not include repetitive anxious questioning. It can include discussing concerns about their memory as long as this is meaningful and not dominated by anxiety.

- If a respondent misunderstands the question, you should repeat the question and if they continue to misunderstand, you should move onto the next question.
- If a respondent refuses to answer reassure them and move on to the next question.
- If a carer says that they do not know, you should assure them that you are asking them as they know the person better than anyone else, so you would their best answer to the question.

- If the respondent comments that they do not think that dementia specifically which limits the person with dementia's social function, assure them that the cause of impaired social function does not matter, rather than you wish to get an overall picture of their current state.

Section 2 and 3

- Some concepts are more abstract and it may be difficult for respondents to answer specifically about the frequency of some behaviours. You should encourage all respondents to give their best answer based on the frequency of these behaviours, using the categories provided, but you should be prepared for respondents to give a more general answer.
- If specific wording is challenging for participants to understand, in particular in section 2, you can use alternative terminology to clarify as in *figure 3*.

Figure 3. Alternative wording

Question	SF-DEM wording	Alternative wording
8	Contacted friends or family by phone or computer	The person with dementia should have initiated the contact or had lengthy contact by telephone or computer, i.e. this does not include a relative calling the person with dementia every evening for a very brief phone call to check their safety. Other non-face-to-face communication modes e.g. Skype, Facebook, email are included.
9	Started or taken part in a conversation	The person with dementia should have initiated the conversation or had lengthy/meaningful conversation.
10/11	Talked to others about your feelings or concerns Asked others about their feelings or concerns	The person with dementia should have engaged with conversation about their or others' feelings to ask for or offer advice or support. It should not include repetitive anxious questioning. It can include discussing concerns about their memory as long as this is meaningful and not dominated by anxiety.
12	Been more limited in their topics of conversation	Found it difficult to think of things to say to other people. Struggled to make new conversation.
13	Found other people's conversation unclear	Struggled to follow other peoples' conversations.

14	Been very outspoken about what you really think about things	Been very frank or forthright about things. Not been able to ‘bite your/their tongue’ about things you/they feel strongly about.
17	Found that you don’t want to do things that you would usually	Been less interested or motivated to do social activities you might have normally enjoyed.

Section 4

- When administering section 4, the respondent should not consult the prompt card, as the response options are different. Instead the interviewer should read the options after the question, e.g. ‘Thinking about your/their social life as a whole, how is it now? Would you say it is excellent, good, fair, poor.

Scoring

- Only questions 1-17 are scored. Questions from section 4 are summary questions to facilitate discussion of possible areas for social intervention between clinician and person with dementia.
- Tick the relevant box after each question and, once completed, put the score for each individual question in the grey box, totalling up the scores for sections 1, 2 and 3 and the total score.
- Please note reverse scoring for questions 12-17.